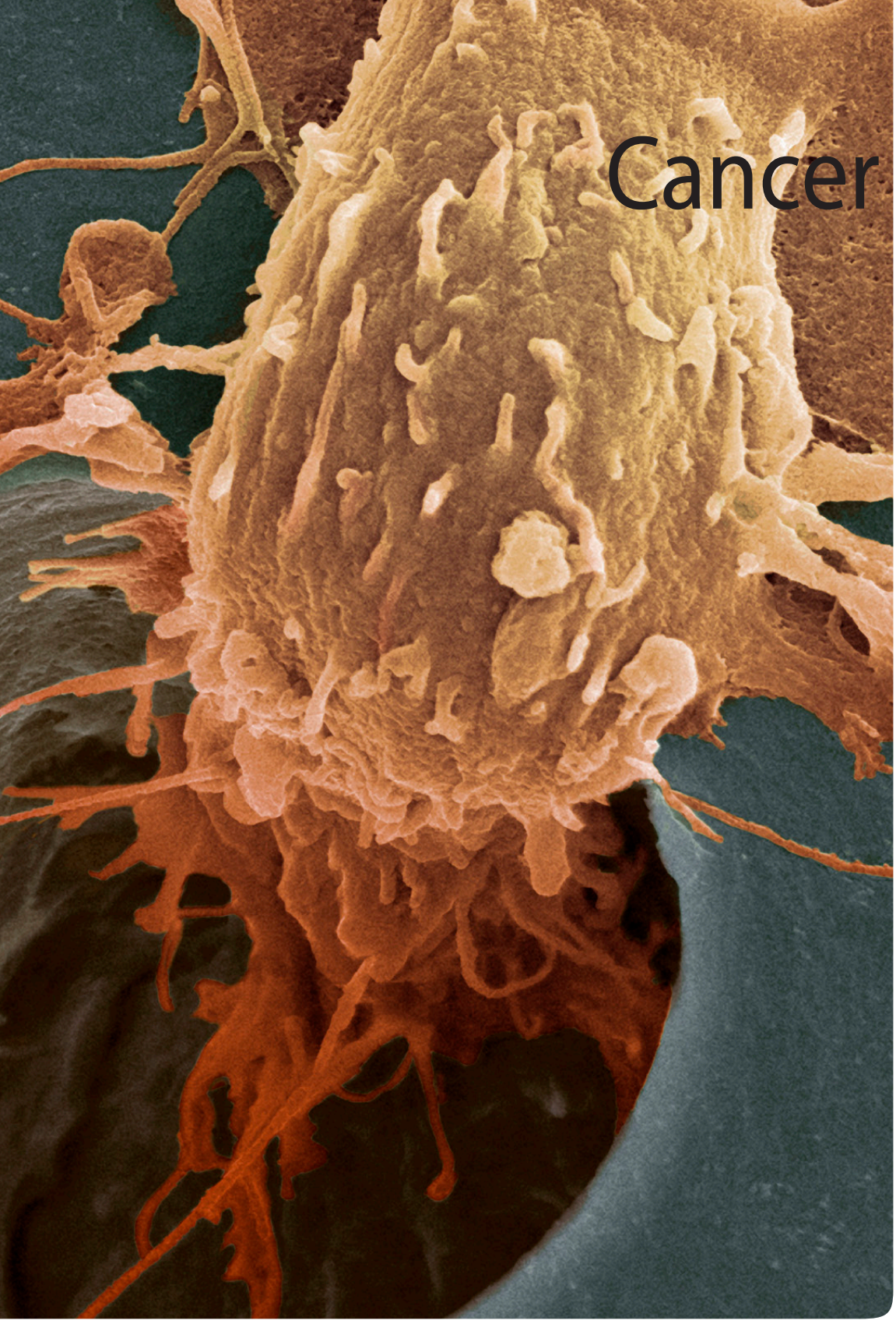
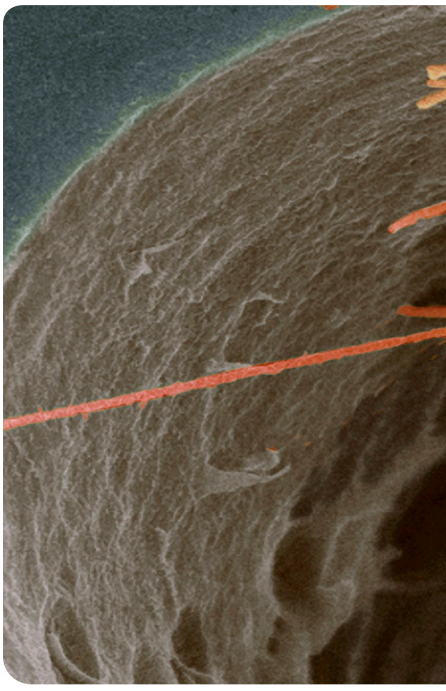
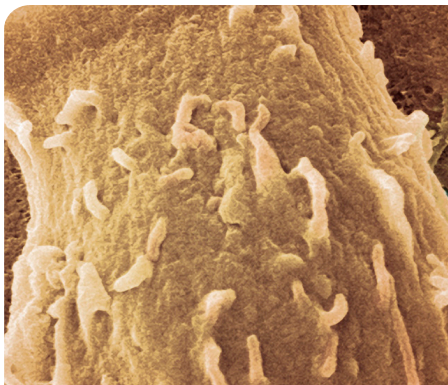


Cancer Clusters

Fact Pack – P045





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Cancer Clusters

Center for Health, Environment & Justice
FactPack - PUB 045

June 2015

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Mentoring a Movement

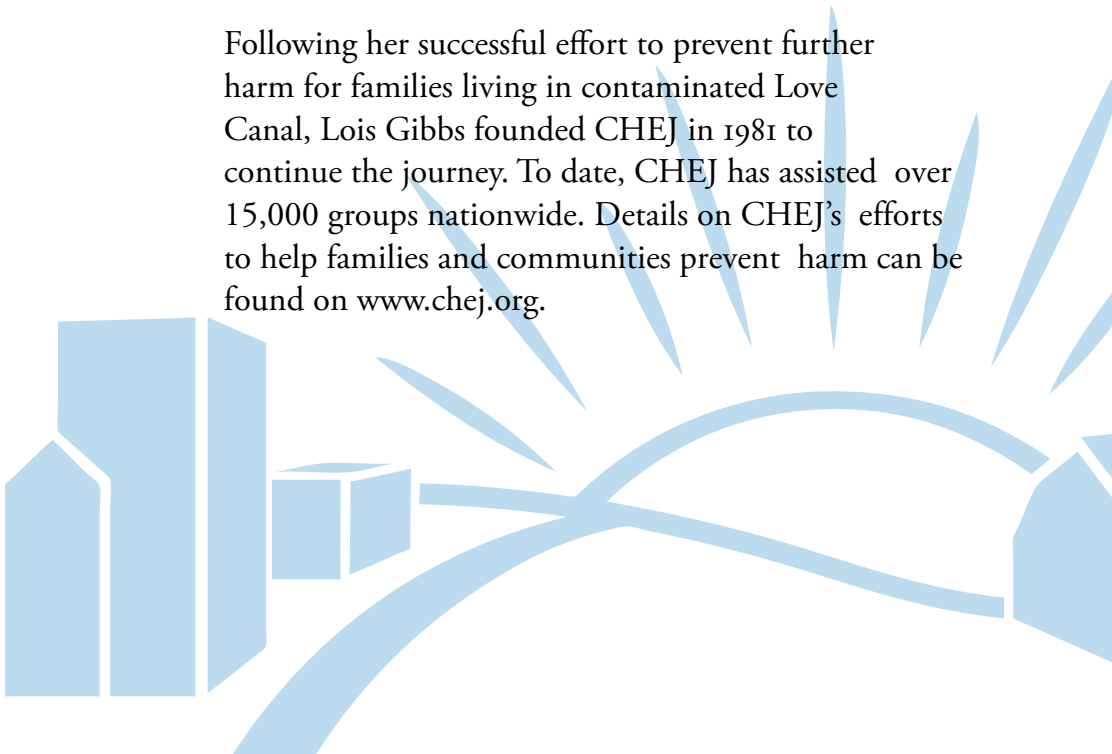
Empowering People

Preventing Harm

About the Center for Health, Environment & Justice

CHEJ mentors a movement building healthier communities by empowering people to prevent harm caused by chemical and toxic threats. We accomplish our work through programs focusing on different types of environmental health threats. CHEJ also works with communities to empower groups by providing the tools, direction, and encouragement they need to advocate for human health, to prevent harm and to work towards environmental integrity.

Following her successful effort to prevent further harm for families living in contaminated Love Canal, Lois Gibbs founded CHEJ in 1981 to continue the journey. To date, CHEJ has assisted over 15,000 groups nationwide. Details on CHEJ's efforts to help families and communities prevent harm can be found on www.chej.org.



INTRODUCTION

The Center for Health, Environment & Justice has developed this fact pack on Cancer Clusters in response to the numerous requests for information that we have had on this topic. This fact pack includes three types of information:

- Selections from technical papers describing cancer and the complexity of identifying cancer clusters.
- Articles that address what needs to be done to protect communities and to get answers.
- News clips and articles describing community struggles and what we know today about cancer clusters.

We have included materials from nonprofit organizations, government agencies, consulting companies, newspapers, and journals in an effort to provide a thorough introduction to the issues. The articles we have chosen highlight what we believe is important information to assist you in educating yourself and others. We do not endorse the conclusions of the government and consulting reports in this fact-pack. We've included them because they provide valuable information describing the politics of cancer and how health studies affect the surrounding community.

Our hope is that reading this fact pack will be the first step in the process of empowering your community to protect itself from environmental health threats. CHEJ can help with this process. Through experience, we've learned that there are four basic steps you'll need to take:

1. Form a democratic organization that is open to everyone in the community facing the problem.

2. Define your organizational goals and objectives.

3. Identify who can give you what you need to achieve your goals and objectives. Who has the power to shut down the landfill? Do a health study? Get more testing done? It might be the head of the state regulating agency, city council members, or other elected officials.

4. Develop strategies that focus your activities on the decision makers, the people or person who has the power to give you what you are asking for.

CHEJ can help with each of these steps. Our mission is to help communities join together to achieve their goals. We can provide guidance on forming a group, mobilizing a community, defining a strategic plan, and making your case through the media. We can refer you to other groups that are fighting the same problems and can provide technical assistance to help you understand scientific and engineering data and show you how you can use this information to help achieve your goals.

If you want to protect yourself, your family, and your community, you need information, but equally important is the need to organize your community efforts.

Thank you for contacting us.

Table of Contents

(Page numbers are listed in upper right hand corner)

Technical Papers on Cancer

Articles Regarding Community Protection and Finding Answers

Community Struggles

Cancer Clusters

Key Points

- Cancer clusters may be suspected when people report that several family members, friends, neighbors, or coworkers have been diagnosed with the same or related cancer(s) (see Defining Disease Clusters section).
- Epidemiologists (scientists who study the frequency, distribution, causes, and control of diseases in populations) investigate suspected cancer clusters (see Facts About Cancer Clusters section).
- Some amount of clustering may occur simply by chance (see Facts About Cancer Clusters section).
- A suspected cancer cluster may be reported to a state or local health department or state cancer registry (see Reporting Suspected Cancer Clusters section).
- Other resources may provide additional information about cancer clusters, cancer incidence and mortality, and environmental risk factors for cancer (see Resources section).

Defining Disease Clusters

A disease cluster is the occurrence of a greater than expected number of cases of a particular disease within a group of people, a geographic area, or a period of time. Clusters of diseases have concerned scientists for centuries. Some recent disease clusters include the initial cases of a rare type of pneumonia among homosexual men in the early 1980s that led to the identification of the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS); the outbreak in 2003 of a respiratory illness, later identified as severe acute respiratory syndrome (SARS), caused by a previously unrecognized virus; and periodic outbreaks of food poisoning caused by eating food contaminated with bacteria.

Cancer clusters may be suspected when people report that several family members, friends, neighbors, or coworkers have been diagnosed with the same or related cancer(s). In the 1960s, one of the best known cancer clusters emerged, involving many cases of mesothelioma (a rare cancer of the lining of the chest and abdomen). Researchers traced the development of mesothelioma to exposure to asbestos, a fibrous mineral that was used heavily in shipbuilding during World War II and has also been used in manufacturing industrial and consumer products. Working with asbestos is the major risk factor (something that may increase the chance of developing a disease) for mesothelioma.

Facts About Cancer

Some concepts about cancer can be helpful when trying to understand suspected cancer clusters:

- Cancer is the uncontrolled growth and spread of abnormal cells anywhere in the body. However, cancer is not just one disease; it is actually an umbrella term for at least 100 different but related diseases.
- Each type of cancer has certain known and/or suspected risk factors associated with it.
- Cancer is not caused by injuries, nor is it contagious. It cannot be passed from one person to another like a cold or flu virus.
- Cancer is almost always caused by a combination of factors that interact in ways that are not yet fully understood.
- Carcinogenesis (the process by which normal cells are transformed into cancer cells) involves a series of changes within cells that usually occur over many years. More than 10 years can go by between the exposure to a carcinogen (any substance that causes cancer) and a diagnosis of cancer, which makes it difficult to pinpoint the cause of that cancer.
- Cancer is more likely to occur as people get older; because people are living longer, more cases of cancer can be expected in the future. This increased life expectancy may create the impression that cancer is becoming much more common, even though an increase in the number of cases of cancer is related in large part to the growing number of elderly people in the population.
- Some racial and ethnic groups have higher rates of cancer than other racial and ethnic groups. Such differences may be due to multiple factors, such as late stage of disease at diagnosis, barriers to health care access, history of other diseases, biologic and genetic differences, health behaviors, and other risk factors.
- Cancer, in general, is common. More than 17 million new cases of cancer have been diagnosed since 1990.

Facts About Cancer Clusters

Reported disease clusters of any kind, including suspected cancer clusters, are investigated by epidemiologists (scientists who study the frequency, distribution, causes, and control of diseases in populations). Epidemiologists use their knowledge of diseases, environmental science, lifestyle factors, and biostatistics to try to determine whether a suspected cluster represents a true excess of cancer cases.

Epidemiologists have identified certain circumstances that may lead them to suspect a potential common source or cause of cancer among people thought to be part of a cancer cluster. A suspected cancer cluster is more likely to be a true cluster, rather than a coincidence, if it involves one or more of the following factors:

- A large number of cases of one type of cancer, rather than several different types.
- A rare type of cancer, rather than common types.
- An increased number of cases of a certain type of cancer in an age group that is not usually affected by that type of cancer.

Before epidemiologists can assess a suspected cancer cluster accurately, they must determine whether the type of cancer involved is a primary (original) cancer or a cancer that has metastasized (spread from another organ). This is important to know because scientists consider only the primary cancer when they investigate a possible cancer cluster. Epidemiologists also try to establish whether the suspected exposure has the potential to cause the reported

cancer, based on what is known about that cancer's likely causes and about the cancer-causing potential of the exposure.

After developing a case definition (the guidelines that determine whether the cases being investigated are related to the cluster), epidemiologists must identify the time period of concern and the population at risk. They then calculate the expected number of cases and compare that number with the observed number of cases. Epidemiologists must show that the number of cancer cases that have occurred is significantly greater than the expected number of cases, given the age, gender, and racial distribution of the group of people at risk of developing the disease.

Epidemiologists must also determine if the cancer cases could have occurred by chance. They often test for "statistical significance," which is a mathematical measure of the difference between groups. The difference is said to be statistically significant if it is greater than what would be expected to happen by chance alone. In common practice, a statistically significant finding means that the probability that the observed number of cases could have happened by chance alone is 5 percent or less. For instance, if one examines the number of cancer cases in 100 neighborhoods, and cancer cases are occurring by chance alone, one should expect to find about five neighborhoods with a statistically significant elevation in the number of cancer cases. In other words, some amount of clustering within the same family or neighborhood may occur simply by chance.

Accurately defining the group of people who should be considered "at risk" is important when investigating a possible cancer cluster. One of the greatest problems in defining clusters is the tendency to expand the geographic borders of the cluster to include additional cases of the suspected disease as they are discovered. The tendency to define the borders of a cluster on the basis of where known cases are located, rather than to first define the population and geographic area and then determine if the number of cancers is excessive, creates many "clusters" that are not real.

Epidemiologists must also consider that a confirmed cancer cluster may not be the result of any single, external cause or hazard. A cancer cluster could be the result of chance, an error in the calculation of the expected number of cancer cases, or differences in the case definition between observed and expected cases. Moreover, because people change where they live from time to time, it can be difficult for epidemiologists to identify previous exposures and find the medical records that are needed to determine the kind of cancer a person had—or if it was cancer at all.

Because a variety of factors often work together to create the appearance of a cluster where nothing abnormal is occurring, most reports of suspected cancer clusters are not shown to be true clusters. Many reported clusters do not include enough cases for epidemiologists to arrive at any conclusions. Sometimes, even when a suspected cluster

has enough cases for study, a greater than expected number of cases cannot be demonstrated. Other times, epidemiologists find a true excess of cases, but they cannot find an explanation for it. For example, a suspected carcinogen may cause cancer only under certain circumstances, making its impact difficult to detect.

Genetics and Environment

Because most cancers are thought to be caused by a combination of factors related to genetics and environment (including behavior and lifestyle), studies of suspected cancer clusters usually focus on these two issues. Genetic factors are inherited, that is, passed from parents to children. However, establishing a genetic-environmental interaction (significant and valid evidence that a specific genetic factor leads to an increased chance that a particular environmental exposure will result in cancer) requires studies of large populations over long periods of time. Researchers are just beginning to learn about the roles genetics and environmental exposures play in carcinogenesis. Some of their discoveries are outlined below:

Genetics

- All cancers develop because of genetic alterations of one kind or another. An alteration is a change or mutation in the physical structure of a gene that interferes with the gene's normal functions.
- Some genetic alterations that increase the risk of cancer are present at birth in the genes of all cells in the body, including reproductive cells. These changes, which are called germline mutations, can be passed from parent to child. This type of alteration is known as an inherited susceptibility; most cancers are not due to an inherited susceptibility.
- Most cancers result from genetic changes that occur after birth during one's lifetime. Genetic changes can occur in any cell that divides. These genetic changes are called somatic alterations.
- Familial cancer clusters (cancer that occurs in families more often than would be expected by chance) have been reported for many types of cancer. Because cancer is a common disease, it is not unusual for several cases to occur within a family. Familial cancer clusters are sometimes linked to inherited susceptibility, but environmental factors and chance may also be involved.
- Having an inherited susceptibility for a type of cancer does not necessarily mean that the individual will be diagnosed with the cancer; it means the chance of developing cancer increases if other factors that promote the development of cancer are present or are encountered later.

Environment

- The term *environment* includes not only air, water, and soil, but also substances and conditions in the home and workplace. It also includes diet; the use of tobacco, alcohol, or drugs; exposure to chemicals; and exposure to sunlight and other forms of radiation.
- People are exposed to a variety of environmental factors for varying lengths of time, and these factors interact in ways that are still not fully understood. Further, individuals have varying levels of susceptibility to these factors.
- Hazardous substances are often found in higher levels in the workplace than in the general environment. For this reason, some workers may have greater and longer exposures to such substances than the general population. Findings of higher than expected numbers of cancer cases among workers in particular occupations or industries provide important leads regarding causes of cancer among the general public. In fact, occupational studies (studies of specific groups of workers) have identified many specific cancer-causing substances and have provided the motivation to find ways to reduce or eliminate exposures in the workplace and elsewhere.

Reporting Suspected Cancer Clusters

A suspected cancer cluster may be reported to a state or local health department or state cancer registry. State and local health departments and cancer registries use established criteria to investigate reports of cancer clusters. When a suspected cancer cluster is first reported, the investigating department or agency gathers information and gives the inquirer general information about cancer clusters. Although investigators may use different processes, most follow a basic procedure in which increasingly specific information is obtained and analyzed in stages. Investigators are likely to request the following:

- Information about the potential cluster: type(s) of cancer, number of cases, suspected exposure(s), and geographic area/time period of concern.
- Information about each person with cancer in the potential cluster: name, address, telephone number, gender, race, age, occupation(s), as well as area(s) lived in/length of time.
- Information about each case of cancer: type of cancer, date of diagnosis, age at diagnosis, possible causes, metastatic sites, and physician contact.

Most reports of suspected cancer clusters are resolved at this initial contact because concerned individuals realize that what seemed like a cancer cluster is not a true cluster. If further evaluation is needed, epidemiologists will take the following steps to investigate a possible cancer cluster:

- Attempt to verify the reported cases by contacting patients and relatives and obtaining medical records.
- Compare the number of cases in the suspected cancer cluster with information in census data and cancer registries to determine if there is a higher than expected number of cases.
- Review the scientific literature to establish whether the reported cancer(s) has been linked to the suspected exposure.
- Work with Federal agencies, if necessary, to gather additional information to help decide whether to conduct a comprehensive epidemiological study.

Resources

The following resources may provide additional information about cancer clusters, cancer incidence (the number of new cases) and mortality (the number of deaths), and environmental risk factors for cancer:

- Local and state health departments are listed under such headings as "health department" and "public health commission" in the blue pages of Government listings in telephone books. In addition, links to state and selected local health department Web sites can be found at http://www.cdc.gov/nceh/clusters/statelocal.htm on the Internet.
- State cancer registries collect data on cancer incidence and mortality. The data in these registries can be used to compare expected cancer rates in certain categories, such as geographic area, gender, age, or racial group, with rates reported in a suspected cancer cluster to determine whether there is a true excess of cases. State cancer registries are listed under such headings as "health department" and "public health commission" in the blue pages of Government listings in telephone books. Contact information for state cancer registries can also be found at http://apps.nccd.cdc.gov/cancercontacts/npcr/contacts.asp on the Internet.

- The **Centers for Disease Control and Prevention's (CDC) National Center for Environmental Health (NCEH**) cancer clusters Web site provides links to cancer cluster resources, answers to frequently asked questions, and an online inquiry form. NCEH can be contacted at:

  Address: Division of Environmental Hazards and Health Effects
  National Center for Environmental Health
  Centers for Disease Control and Prevention
  Re: Cancer Clusters
  Mail Stop F–52
  4770 Buford Highway
  Atlanta, GA 30341
  Telephone: 1–800–232–4636 (1–888–CDC–INFO) (toll-free)
  E-mail : cdcinfo@cdc.gov
  Internet Web site: http://www.cdc.gov/nceh/clusters/

- The **CDC's National Institute for Occupational Safety and Health (NIOSH)** conducts research and makes recommendations for the prevention of work-related disease and injury. Information about possible workplace cancer clusters and how they are evaluated is available on NIOSH's Occupational Cancer Web page at http://www.cdc.gov/niosh/topics/cancer/ on the Internet. NIOSH's Health Hazard Evaluation (HHE) Program investigates potentially hazardous working conditions, including suspected cancer clusters, when employers, authorized employee representatives, or employees request it. The HHE Program can be contacted at:

  Address: Hazard Evaluation and Technical Assistance Branch
  NIOSH
  Mail Stop R–9
  4676 Columbia Parkway
  Cincinnati, OH 45226
  Telephone: 1–800–356–4674 (1–800–35–NIOSH) (toll-free)
  Internet Web site: http://www.cdc.gov/niosh/hhe

- The **Agency for Toxic Substances and Disease Registry (ATSDR),** an agency of the U.S. Department of Health and Human Services (DHHS), conducts public health assessments of waste sites, performs health consultations concerning specific hazardous substances, maintains health surveillance and registries, responds to emergency releases of hazardous substances, and provides education and training concerning hazardous substances. Contact information for ATSDR regional offices can be found at http://www.atsdr.cdc.gov/DRO/dro_contact.html on the Internet. The ATSDR can be contacted at:

  Telephone: 1–800–232–4636 (1–800–CDC–INFO)
  TTY: 1–888–232–6348
  Internet Web site: http://www.atsdr.cdc.gov

- The **National Institute of Environmental Health Sciences (NIEHS)**, a part of the National Institutes of Health (NIH), studies how environmental exposures, genetic susceptibility, and age interact to affect an individual's health. The NIEHS can be contacted at:

  Address: The National Institute of Environmental Health Sciences
  Post Office Box 12233
  Research Triangle Park, NC 27709
  Telephone: 919–541–3345
  Internet Web site: http://www.niehs.nih.gov

- The **Occupational Safety and Health Administration's (OSHA) Office of Occupational Medicine** performs workplace-related case evaluations and cluster investigations, including medical record review, employee interviews, and medical screening activities. OSHA can be contacted at:

Address: Office of Occupational Medicine
Occupational Safety and Health Administration
U.S. Department of Labor
Room N3457
200 Constitution Avenue, NW.
Washington, DC 20210
Telephone: 202–693–2323
Internet Web site: http://www.osha.gov/dts/oom/index.html

- The **Where You Live** Web page, which is managed by the U.S. Environmental Protection Agency (EPA), allows users to enter a ZIP Code and choose from four databases to retrieve environmental information about a community or to locate a regional office. This resource is available at http://www.epa.gov/epahome/whereyoulive.htm on the Internet.

- The **National Cancer Institute (NCI),** another component of the NIH, has the **Cancer Mortality Maps and Graphs** Web site, which provides interactive maps, graphs, text, tables, and figures showing geographic patterns and time trends of cancer death rates for the time period 1950–94 for more than 40 cancers. It also provides interactive mortality charts and graphs, customizable mortality maps, and links to related domestic and international Web sites, including a link to the online publication of NCI's *Atlas of Cancer Mortality in the United States: 1950–94*. The NCI's Cancer Mortality Maps and Graphs Web site can be accessed at http://www3.cancer.gov/atlasplus/ on the Internet.

# # #

Related NCI materials and Web pages:

- National Cancer Institute Fact Sheet 6.7, *Cancer: Questions and Answers* (http://www.cancer.gov/cancertopics/factsheet/Sites-Types/general)
- *Cancer and the Environment: What You Need To Know, What You Can Do* (http://www.cancer.gov/newscenter/Cancer-and-the-Environment)
- *What You Need To Know About™ Cancer* (http://www.cancer.gov/cancertopics/wyntk/cancer)

How can we help?

We offer comprehensive research-based information for patients and their families, health professionals, cancer researchers, advocates, and the public.

- ***Call*** NCI's Cancer Information Service at 1–800–4–CANCER (1–800–422–6237)
- ***Visit*** us at http://www.cancer.gov or http://www.cancer.gov/espanol
- ***Chat*** using LiveHelp, NCI's instant messaging service, at http://www.cancer.gov/livehelp
- ***E-mail*** us at cancergovstaff@mail.nih.gov
- ***Order*** publications at http://www.cancer.gov/publications or by calling 1–800–4–CANCER
- ***Get help*** with quitting smoking at 1–877–44U–QUIT (1–877–448–7848)

This fact sheet was reviewed on 10/5/06

Centers for Disease Control and Prevention
CDC 24/7: Saving Lives. Protecting People.™

Cancer Clusters

A **cancer cluster** is defined as a greater-than-expected number of cancer cases that occurs within a group of people in a geographic area over a period of time.

To be a cancer cluster, a group of cancer cases must meet the following criteria. Until all of these parameters are met, the group of cancer cases is often referred to as a **suspected cancer cluster**.

- *A greater than expected number:*
  A greater than expected number is when the observed number of cases is higher than one would typically observe in a similar setting (in a group with similar population, age, race, or gender). This may involve comparison with rates for comparable groups of people over a much larger geographic area – e.g., an entire state.
- *Of cancer cases:*
  All of the cases must involve the same type of cancer, or types of cancer scientifically proven to have the same cause.
- *That occurs within a group of people:*
  The population in which the cancers are occurring is carefully defined by factors such as race/ethnicity, age, and gender, for purposes of calculating cancer rates.
- *In a geographic area:*
  Both the number of cancer cases included in the cluster and calculation of the expected number of cases can depend on how we define the geographic area where the cluster occurred. The boundaries must be defined carefully. It is possible to "create" or "obscure" a cluster by selection of a specific area.
- *Over a period of time:*
  The number of cases included in the cluster – and calculation of the expected number of cases – will depend on how we define the time period over which the cases occurred.

In the 1960s, one of the best known cancer clusters emerged, involving many cases of mesothelioma (http://www.cancer.gov/dictionary?expand=m#mesothelioma) (http://www.cdc.gov/Other/disclaimer.html) (a rare cancer of the lining of the chest and abdomen (http://www.cancer.gov/dictionary?expand=a#abdomen) (http://www.cdc.gov/Other/disclaimer.html)). Researchers traced the development of mesothelioma to exposure to asbestos (http://www.cancer.gov/dictionary?expand=a#asbestos) (http://www.cdc.gov/Other/disclaimer.html) , a fibrous mineral (http://www.cancer.gov/dictionary?expand=m#mineral) (http://www.cdc.gov/Other/disclaimer.html) that was used heavily in shipbuilding during World War II and has also been used in manufacturing industrial and consumer products. Working with asbestos is the major risk factor (something that may increase the chance of developing a disease) for mesothelioma.

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800-CDC-INFO (800-232-4636) TTY: (888) 232-6348 - Contact CDC-INFO

Region 2

Cancer Clusters

A cluster is the occurrence of a greater than expected number of cases of a particular disease within a g geographic area, or a period of time.

Epidemiologists have identified certain conditions that should be considered before reporting a suspecte suspected cancer cluster is more likely to be a true cluster if it involves a large number of cases of one t several different types; a rare type of cancer, rather than common types; or a number of a certain type groups not usually affected by that type of cancer.

Local and state health departments are responsible for conducting cancer cluster studies and are the ag cluster should be reported. The Centers for Disease Control and Prevention and other Federal agencies, responsible for cluster studies, are now called in only for special situations.

More information is available from the following: EXIT Disclaimer

The National Cancer Institute
A primary fact sheet on cancer clusters and risk factors, plus additional cancer-related links.

National Cancer Institute Research on Childhood Cancers
A fact sheet on cancer in children, including information on cancer clusters.

National Institute of Environmental Health Sciences
reprint of an article from the journal "Environmental Health Perspectives" which deals with childh information about cancer clusters among children.

Centers for Disease Control (CDC)
Guidelines for Investigating Clusters of Health Events

CA Cancer J Clin 2004;54:273–280

Understanding Cancer Clusters

Michael J. Thun, MD, MS; Thomas Sinks, PhD

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Dr. Sinks is Associate Director for Science, National Center for Environmental Health, Centers for Disease Control and Prevention, Atlanta, GA.

The article is available online at: http://CAonline.AmCancerSoc.org

ABSTRACT Each year, state and local health departments respond to more than 1,000 inquiries about suspected cancer clusters. Three quarters of these reports involve situations that are clearly not clusters and can be resolved by telephone. For the remainder, follow-up is needed, first to confirm the number of persons affected, their age, type of cancer, dates of diagnosis, and other factors, and then to compare cancer incidence in the affected population with background rates in state tumor registries. In approximately 5% to 15% of the reported situations, formal statistical testing confirms that the number of observed cases exceeds the number expected in a specific area, given the age, sex, and size of the affected population. Even in these instances, however, chance remains a plausible explanation for many clusters, and further epidemiologic investigation almost never identifies the underlying cause of disease with confidence. The few exceptions have involved clusters of extremely rare cancers occurring in well-defined occupational or medical settings, generally involving intense and sustained exposure to an unusual chemical, occupation, infection, or drug. This article discusses the resources and scientific tools currently available to investigate cancer clusters. It also provides a framework for understanding cancer clusters and a realistic appraisal of what cluster investigations can and cannot provide in the context of community expectations. (*CA Cancer J Clin 2004;54: 273–280.*)

INTRODUCTION

The public image of cancer clusters, popularized by Hollywood movies such as *A Civil Action* and *Erin Brockovich*, is that any collection of people diagnosed with cancer may represent a mini-epidemic caused by local environmental contamination.[1] Toxic exposures are presumed to be a major cause of human cancers. Any apparent clustering of cancer cases in a geographic area, time period, and/or defined group of people raises the specter that a localized source of pollution may be causing the problem. Public concern focuses primarily on toxic exposures, even when the perceived cluster involves a school, suburban neighborhood, or office building where the likelihood of such exposures appears no different from that in many other unaffected settings.

Epidemiologists and public health workers who investigate suspected cancer clusters are more skeptical of the scientific value of cluster investigations than is the general public. They recognize the historical examples in which clustering of rare types of cancer among highly exposed occupational and medical populations has led to the recognition of human carcinogens.[2,3] However, they distinguish between these situations, where the exposure is high, prolonged, and well defined, and community settings in which exposures are low and poorly defined, where the cases may involve a mix of unrelated, relatively common types of cancer, and the scientific tools available to investigate these situations rarely identify an underlying cause with confidence. More than 1,000 suspected cancer clusters are reported to state health departments each year.[4–6] About three quarters of these are clearly not clusters and can be resolved by telephone if health officials respond promptly and with sensitivity to the requester using clearly defined criteria to evaluate and triage the reports.[7] In approximately 5% to 15% of the reported situations, formal statistical testing confirms that the number of observed cases exceeds the number expected in the affected population, given the age, sex, number of people at risk, and the time period of observation.[7] However, even in these settings, epidemiologic studies are rarely definitive, and chance remains a plausible explanation for the clustering.

The goal of this article is to provide a framework for understanding and responding to cancer clusters so that affected communities can realistically anticipate what investigations can and cannot provide. We describe the criteria

that define a cancer cluster, selected historical examples of clusters that contributed to the discovery of previously unrecognized human carcinogens, the steps involved in investigating a suspected cancer cluster, and considerations that may complicate or impede such investigations in community settings.

WHAT IS A CANCER CLUSTER?

The term cancer cluster usually implies that more cases of cancer (usually of the same type) are identified within a certain group of people, geographic area, and time period than are expected, based on the size and age of the population. Usually the term refers to a highly localized situation such as a school, neighborhood, or workplace, although it is sometimes used to refer to a broader geographic area or larger subgroup of the population. Concern about disease clustering is not exclusive to cancer. Similar concerns apply to birth defects, neurologic diseases, and other conditions for which the etiology is obscure. Some suspected cancer clusters involve a combination of cancers with other diseases possibly related to pollution.

Epidemiologists and public health workers who respond to concerns about clusters distinguish between perceived clusters, those that have been noticed and reported but not yet formally evaluated, and confirmed clusters, in which the case diagnoses and their connection to the community have been documented, and statistical testing indicates a very low probability that the observed clustering could occur by chance.[8] The number of perceived cancer clusters reported to public health agencies is much larger than commonly appreciated. Although records are not collected routinely nationwide, 41 state health departments recorded approximately 1,900 inquiries about cancer clusters in 1996.[6] Other surveys provide lower estimates, ranging from 1,300 to 1,650 reports in 1989[5] to 1,100 in 1997.[4] Records from the Missouri Department of Health document 101 inquiries about cancer clusters received between 1984 and 1988.[9] A similar number of reports were recorded by the Health Departments in Wisconsin and Minnesota during other five-year time periods.[7,10] A search of US newspaper articles containing the words "cancer cluster" identified 2,006 reports filed from January 5, 1990 to January 5, 2000.[8]

In practice, only a small fraction of suspected cancer clusters meet statistical criteria of a confirmed cluster, in which chance is unlikely to explain the excess of observed cases over the expected amount. Of the 101 potential cancer clusters evaluated formally by the Missouri Department of Health between 1984 and 1988, only 17 had a statistically significant excess number of observed compared with expected cases.[9] Only 5% of perceived clusters evaluated by the Minnesota Department of Health were statistically significant.[7] In many cases, perceived clusters include different types of cancers, benign or metastatic tumors, cases that had little connection with the community, or cases that occurred over a longer time period than appreciated. Even when an investigation documents that a given clustering is "statistically significant" (meaning that there is less than a 5% chance that the observed number of cases could have occurred by chance), this does not rule out chance, given the potential for random aggregation in a country the size of the United States. The interpretation of statistical significance in the context of disease clustering is discussed further below.

HISTORICALLY INFORMATIVE CANCER CLUSTERS

There are well-known instances in which the investigation of an unusual cancer cluster has led to the identification of a previously unrecognized human carcinogen. All of the examples listed in Table 1 involved clusters of a rare type of cancer in people with prolonged, high-intensity exposure to industrial or medical carcinogens.[2] Each was recognized as extraordinary by an alert clinician and reported to public health and medical officials for evaluation. Although such examples are rare, even in occupational settings, they illustrate how some cancer clusters can provide new scientific information about the causes and prevention of cancers. One of the earliest reports of a cancer

TABLE 1 Examples of Cancer Clusters Leading to Identification of Human Carcinogens

Classification	Year	Cancer Cluster
Occupational	1775	Scrotal cancer in chimney sweeps exposed to soot from coal.
	1929	Osteosarcoma in watch dial painters exposed to radium.
	1965	Mesothelioma and lung cancer in asbestos workers.
	1974	Angiosarcoma of the liver in chemical workers exposed to vinyl chloride monomer.
Medical	1971	Vaginal clear cell carcinoma in daughters exposed in utero to diethylstilbestrol.
Other	1981	Kaposi sarcoma in homosexual men with AIDS exposed to human herpes virus B.

cluster involved scrotal cancer among London chimney sweeps in the 18th century.[11] Young boys employed in this occupation were exposed to soot from coal while crawling through the narrow chimneys and from their unlaundered clothing. Another tragic example, early in the 20th century, was a cluster of women diagnosed with osteosarcoma of the jaw while employed as watch dial painters in New Jersey and Connecticut.[12] These women were exposed to ionizing radiation from radium present in the luminous paint when they used their lips to form a sharp tip on the paintbrush. Other clusters involved pleural mesothelioma among asbestos workers in London[13] and angiosarcoma of the liver among chemical workers exposed to vinyl chloride monomer.[14] In each case, the occupational exposure was high and prolonged. The exposures that result from medical treatment or chronic infections are also considerably higher than those involving exposure to pollutants in the general community. The recognition of a cluster of adenocarcinoma of the vagina in young women whose mothers had been treated with diethylstilbestrol (DES) led to the identification of DES as a transplacental carcinogen.[15] A cluster of Kaposi sarcoma and *Pneumocystis carinii* pneumonia in healthy gay men contributed to the discovery of the acquired immune deficiency syndrome epidemic and the human immunodeficiency virus.[16]

These examples are much less common than more recent investigations that have not identified any specific cause of the apparent clustering. There have been numerous investigations near high-tension power lines, nuclear facilities, hazardous waste dumps, neighborhoods, schools, and office buildings that have not provided new scientific information about the causes or prevention of cancer, nor have they convincingly identified a reason for apparent clustering.

HOW ARE SUSPECTED CANCER CLUSTERS INVESTIGATED?

Public health officials from state and local health departments usually take primary responsibility for responding to perceived clusters. Most states have developed a stepwise approach to triage requests from the public, using established criteria to determine their response.[7,17] Some states regularly analyze cancer registry data to identify communities with more cancers than expected. Others do not investigate reported clusters but rather limit their activity to cancer education.

Federal agencies that provide assistance to states in investigating certain clusters include the Centers for Disease Control and Prevention (CDC) (http://www.cdc.gov/nceh/clusters/), the National Cancer Institute (NCI) (http://seer.cancer.gov), and the Environmental Protection Agency (http://www.EPA.gov). The CDC has proposed Guidelines for Investigating Clusters of Health Events (http://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm). The National Institute for Occupational Safety (NIOSH) is the lead federal agency within the CDC for investigating occupational cancer clusters. The National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry (http://atsdr1.atsdr.cdc.gov) are other agencies within the CDC that may consult with health departments and are sometimes asked to

conduct field and laboratory studies of community clusters. Both the National Center for Chronic Disease Prevention and Health Promotion of the CDC and the NCI support population-based cancer registries that monitor the background incidence rate of cancers, against which suspected clusters are compared. Other sources of information are the American Cancer Society (ACS) (http://www.cancer.org), the Cancer Information Service (http://www.cis.org),[18] and the Council of State and Territorial Epidemiologists (http://www.cste.org).

The initial steps in investigating perceived cancer clusters are straightforward. Health workers inquire about the number of people who have developed cancer, their age, type of cancer, dates of diagnosis, and period of residence in the community. Where appropriate, officials may obtain medical records to confirm the diagnoses and collect supplemental clinical information.[19] In many instances, perceived cancer clusters are not confirmed because the cases involve different types of cancers with no known relationship to each other, health conditions other than malignancy, or diagnoses made before moving into the community. Discussions at this point may alleviate public concern by documenting the absence of a cluster. Depending on the circumstances, review of environmental monitoring data may also be indicated.

Formal statistical testing involves comparing the observed number of cases with the number expected, based on the size and age composition of the population. The expected number of cases is estimated by applying background incidence rates at various ages in the general population (from cancer registry data) to the population of interest. For the comparison to be valid, it is essential that identical criteria be used to define cases and persons at risk in the two populations. For example, only people who live in the community at the time of their diagnosis should be counted among the observed cases. Those diagnosed before or after their period of residence should not be included, because state tumor registries only capture cancers diagnosed during the period of residence. The expected number of cases increases with each year of observation. Thus, the number of cases expected in a single year should be multiplied by the number of years over which cases in the perceived cluster occurred.

Complexities of Statistical Testing

Despite the value of statistical testing, chance remains the most plausible explanation for many confirmed cancer clusters, especially those that involve common types of cancer or all cancers combined. Because of the increase in life expectancy and the strong relationship between cancer risk and aging, cancers are more common than recognized. About one of every two men and one in every three women will develop cancer over full life expectancy. Given that an estimated 1,368,000 new diagnoses and 563,700 deaths from cancer are expected in 2004,[20] some spatial clustering is inevitable. For instance, a city of 100,000 people with the same age distribution as the United States can, on average, expect 473 new cases and 200 deaths from cancer each year. Even if these cases occur randomly, some clustering will occur by chance. However, the communities affected by clustering may not perceive their experience as part of a larger random pattern, but as the direct consequence of some local underlying cause. This interpretation is analogous to the Texas "sharpshooter" who first fires his shots randomly at a wall and then draws a bull's-eye around a cluster of bullet holes.[21] The fact that the boundaries of a suspected cluster are defined based on when and where the cases actually occurred increases the likelihood that random variation will appear to give rise to clusters.

WHY ARE INVESTIGATIONS OF COMMUNITY CANCER CLUSTERS DIFFICULT?

Many factors limit the information that can be gained by investigating cancer clusters, especially in community settings. The levels of exposure to industrial or agricultural pollutants are much lower and more difficult to assess in nonoccupational settings than in many workplaces; the populations at risk are less clearly

defined. Even when exposure levels exceed environmental standards, the expected increase in risk from community exposures would be detectable only in very large populations rather than in localized clustering. Although certain individuals, such as pregnant mothers and children, may be especially susceptible to toxic and carcinogenic exposures, the size of these groups is usually too small in any single community to support extensive statistical analyses. Epidemiologic methods that can provide strong evidence of association in large studies have limited value in cluster investigations, especially in the absence of documented high-level exposure. Finally, environmental monitoring of current exposures may not satisfy skeptics who contend that past exposures were probably higher and more relevant than current exposures to the development of cancer in the affected individuals.

Another problem that complicates studies in community settings arises from inaccurate data on the population at risk in small geographic areas or demographic subgroups. Census data are less accurate for cities or counties than for states. The uncertainty is greatest for demographic subgroups of the population during the 10-year interval between national census counts. Two recent examples illustrate this problem. The first involves a report of higher cancer incidence and mortality among African Americans in Atlanta than in other areas covered by NCI registries.[22] Compared with average death rates among African Americans, African American residents of Atlanta appeared to have 40%, 19%, and 16% higher mortality rates from prostate, breast, and colon cancer, respectively, during the 1990s. When updated population data were released from the 2000 census, however, the death rate from these cancers was seen to be similar in African Americans across all of the NCI registries. The higher estimates during the 1990s resulted from an underestimation of migration of African Americans into Atlanta during that period.

A second related example concerns the apparent rapid increase in breast cancer incidence in Marin County, California during the 1990s. Breast cancer incidence was reported to increase by 3.6% per year in Marin County between 1990 and 1999.[23] This increase, which was confined to non-Hispanic White women aged 45 to 64 years, appeared to be six times larger than the increase in other counties in the San Francisco Bay Area. However, a reanalysis based on population data from the 2000 census, rather than projections from the 1990 census, revealed that breast cancer incidence in Marin County had not actually increased more rapidly than in adjoining counties.[24] Rather, projections from the 1990 census underestimated the number of non-Hispanic White women aged 45 to 64 who moved into Marin County in the 1990s. Although breast cancer incidence is high in Marin County, as in other affluent counties, the alarming increase in incidence reported during the 1990s appears to have been an artifact of inaccurate projections of the underlying population.

Regardless of the setting of a suspected cancer cluster, investigations are also complicated by the lack of clinical or molecular tests that can determine the cause of cancer in an individual. Until such tests are developed, researchers must rely on epidemiologic studies that can identify factors associated with risk in groups of people, but not the precise cause of disease in an individual. Because of these difficulties, even extensive investigations of cancer clusters are rarely successful in determining the cause of clusters in community settings. For example, the CDC systematically investigated a series of 108 community cancer clusters reported from 29 states and five foreign countries in the years 1961 to 1982.[25] In none of these did the researchers consider the cause to be well established. NIOSH investigated 61 suspected occupational cancer clusters during the period of 1978 to 1984, most of which included five or fewer cases and had no plausible occupational etiology.[26] In such cases, the apparent cluster is attributed either to chance or to exposures that could not be documented using the investigative tools available at the time.

Despite the many obstacles to investigating cancer clusters in the community, some clusters may nevertheless have common etiologic factors that have not yet been identified. For instance, numerous clusters of childhood

leukemia, and to a lesser extent lymphoma, are reported in the scientific literature. Leukemia clusters have been recorded in Europe since the beginning of the 20th century.[27] The first extensive investigations of such clusters were conducted in Northumberland, England[28] and Niles, Illinois[29] in the early 1960s. Other investigations of childhood leukemia have generated scientific and media interest, such as the cluster near a nuclear power plant in Sellafield, England.[30,31] An exceptionally large cluster of childhood leukemia occurred in Churchill County (Fallon), Nevada from 1997 to 2001. Eleven cases of leukemia were identified over a five-year period among children in a community of 26,000 people. Four others who had previously lived in the area but had moved away were also diagnosed with leukemia. Only one case every five years would be expected among the resident population of this age, based on average incidence rates in Nevada.[32] Extensive investigation failed to identify an underlying cause for the clustering. Although most statistical analyses suggest that clusters of childhood leukemia occur somewhat more frequently than would be predicted by chance,[27,33] such clustering explains only a small fraction of incident cases. Researchers have hypothesized that an as yet unidentified infectious exposure occurring at a particular stage in development may give rise to these clusters.

When is an Extensive Investigation Appropriate?

There are many more reports of suspected cancer clusters than can or should be investigated extensively. The goals of an initial evaluation are to respond to community concerns, to document the facts of what has happened (and thereby minimize the influence of rumor), and to assist the community in determining and implementing the appropriate response. While it is critical to triage reported clusters to determine which should be investigated more thoroughly, it is equally important to hear the community's concerns and provide information about how reports of cancer clusters are evaluated and what has been learned. Approaches that can improve communication with the community are discussed below.

In some cases, further investigation of a documented cancer cluster is indicated. Increasingly, epidemiologic studies of the community are only conducted when the following conditions are met: (1) the observed number of cases of a specific type of cancer significantly exceeds the number expected; (2) either the type of cancer or age at onset is highly unusual; (3) the population at risk can be defined; and (4) prolonged exposures to known or suspected carcinogens at levels that exceed environmental limits can be documented. The demand for further investigation is greatest when new cases continue to be diagnosed. Further environmental monitoring and/or review of environmental data may be indicated in situations with an identifiable source of contamination. This may be useful to document local contamination and stimulate cleanup. However, the community should be informed in advance that environmental measurements rarely resolve controversy about the cause of the cluster and will not, by themselves, provide scientifically convincing evidence linking the cluster to environmental exposure. The decision of whether or not to conduct further investigation of a cancer cluster is, in most cases, difficult. To some it may appear negligent not to explore every possible explanation for the apparent cluster. However, the desire to "leave no stone unturned" is not in itself a sufficient reason to conduct extensive environmental monitoring or medical testing. Professional judgment about the likelihood of whether further investigation will be informative should help to guide health officials and communities confronting these difficult situations.

Following the completion of an investigation, state health departments may continue to monitor cancer occurrence in the local community and the surrounding county for three to five years.[6,9,31] It is presumed that an observed "excess" of cancer cases due to chance will not continue and that the incidence rate will return to the expected range during this

period. If the rate remains elevated, further studies may be performed.[7,9,10]

Talking with the Community

Perhaps the most important challenge for public health agencies that deal with cancer clusters is to communicate effectively with the public. This has been described as the "art of being responsibly responsive."[7] State or local health departments usually take primary responsibility for this; physicians in the community can serve an essential role. Communication should begin early, before divergent points of view become highly polarized. It is often helpful to convene a public meeting to hear specific concerns and varying points of view. This provides an opportunity to explain what is known, what steps are being taken to investigate the situation, and to provide background information about suspected cancer clusters. The effectiveness of such a meeting depends on speakers who have considerable experience and credibility in medicine, public health, and cluster investigations and who are able to interact effectively with an alarmed public. Credibility is enhanced by the endorsement of respected leaders of the community with no financial stake in the outcome of an investigation. The goal is to provide a structured process within which individuals can voice their concerns and support informed community decision making.

Potential Roles for Physicians

Physicians are a respected source of information about health and disease. Their extensive interactions with patients and their families provide opportunities to reassure patients in situations that are unlikely to involve a cancer cluster, educate patients about ways to avoid cancers or identify them early, and identify settings that warrant investigation by public health agencies. Physicians may live in communities affected by a suspected cancer cluster. In such cases, an informed doctor can contribute to the public debate by providing background information about cancer and cancer clusters and by realistically describing what can or cannot be learned by exhaustive investigation of environmental exposures. Public concern about cancer clusters provides broader opportunities to educate patients and community leaders about cancer and the value of proven strategies of prevention and early detection.

CONCLUSIONS

In recent decades, considerable public health energy has been invested in the investigation of reported cancer clusters. Responding to such clusters is a legitimate and necessary public health activity,[7] but many state and local health departments have limited resources to respond to the number of perceived clusters reported each year. Informed clinicians can play an important role by helping to educate patients and their families about cancer and by contributing to public debate and decision making.

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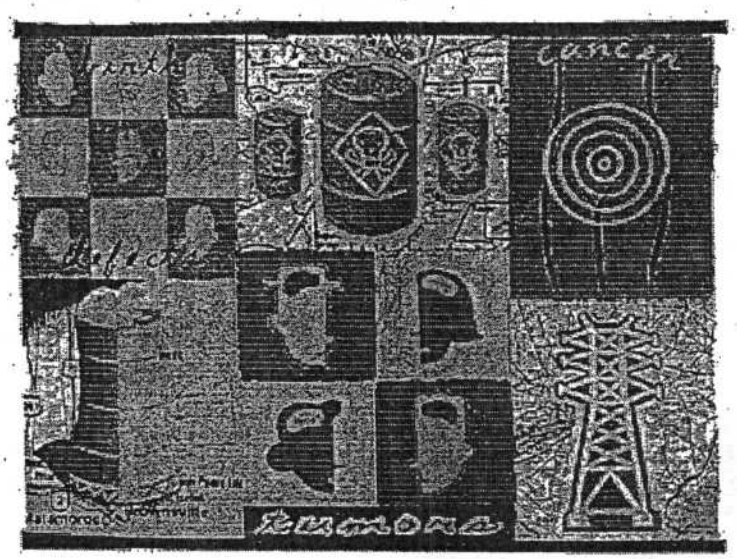
CANCER CLUSTERS

The complexities of mapping out clear cause and effect cancer relationships

By Darrell E. Ward



When officials at River Valley High School outside of Marion, Ohio, became concerned about the number of school graduates who had developed leukemia, they reported their fear to the Ohio Department of Health.

The concern involved seven students who had developed leukemia sometime after graduation-whereas, according to the state health department, only two cases normally would have been expected. Moreover, an investigation by the state health department revealed that the death rate from leukemia in Marion had risen 122 percent in the last 30 years.

The Columbus Dispatch reported William Ryan, director of the Ohio Department of Health, as saying in October 1997, "There is a problem. But we can't even say if it's environmental in nature. It could be genetic. It could be the result of immune deficiency. It could be a whole host of things."

It also could be due to random chance.

The mayor of Marion, Jack Kellogg, was reported to have called news of the death rate "alarming," and said he would do all he could to slow it down. The Dispatch also quoted then-Ohio governor George Voinovich as ordering state investigators "to leave no stone unturned in trying to answer these questions."

The grounds where the school stood had been an ammunition dump and supply depot during and shortly after World War II, so the Ohio Environmental Protection Agency and the Army Corps of

Engineers were called in to run tests of the air, soil, and water in and around the school. Soil testing showed contamination by a known carcinogen, benzo-a-pyrene, in the soil that covered a former dirt road at the site.

Investigations of disease clusters can identify important public health problems, but unless the disease is extremely rare, highly unusual in a particular group, or previously unknown, establishing a clear cause can be extremely difficult.

More testing would be done. The question was, when the time came to determine what all the tests and findings meant, would either the parents or the health officials be happy with the results? If history is any indicator, the answer to that question is probably not.

River Valley High School represents one of dozens, if not hundreds, of cancer clusters under investigation around the United States each year. Examples of visible cancer clusters that received high media exposure include one in Woburn, Mass., which was the basis for the movie A Civil Action, starring John Travolta; a brain tumor cluster in Toms River, N.J.; and another brain tumor cluster in workers at an Amoco research laboratory in Naperville, Ill.

Cancer clusters that receive only local publicity but that can generate grave concerns happen every year in every state in the country. In 1997, Kim Blindauer, an epidemiologist for the Centers for Disease Control (CDC), did an informal survey to estimate how many calls were received by state health departments about cancer clusters during the previous year. The 41 states that responded received a total of about 1,900 reports from people worried about "too much cancer" in their community, neighborhood, or county. "In my opinion, that is an underestimate," said Blindauer. She sent her survey only to health departments, but similar calls are handled by other state offices such as tumor registries, departments of chronic disease and of natural resources, and offices of environmental protection or environmental quality.

Randall Harris Deborah Gray

Each suspected cancer cluster represents the fear of citizens who believe something in their town, community, schools, or workplace is causing cancer. It's a devastating fear, one that violates people's sense of safety and security as surely as a burglary. As in Marion, cancer clusters often involve the safety of children, and they can affect jobs and property values.

Cancer clusters represent people's fear that they are surrounded by cancer-causing agents: a nearby waste dump, a local industry, chemicals in their food, a neighboring broadcast tower, electromagnetic radiation from high-voltage power lines, contaminated water.

People tend to see cause and effect between such agents and their perception of the cancer rate in their

community. But establishing that such a relationship truly exists is extremely difficult.

Investigations of disease clusters can identify important public health problems, but unless the disease is extremely rare, highly unusual in a particular group, or previously unknown, determining a clear cause and effect is problematic.

As a result, few cancer clusters are resolved to the community's satisfaction. In spite of the best efforts of local public health officials, federal health workers, and regulatory agencies, the investigation of clusters can leave some people dissatisfied, frustrated, even angry.

The ultimate source of this frustration, for citizens and public health officials alike, is the complex nature of cancer and the difficulty in establishing the cause and effect relationship. For public health departments, suspected cancer clusters are at once a responsibility, a burden, and an opportunity for community education.

In short, cancer clusters must be handled carefully, responsibly, and with sensitivity by those who suspect-and fear-they have detected one in their community, by the health officials who are investigating, and by the media.

The good news is that cancer clusters rarely hold up under close scrutiny.

Defining cancer

Cancer is not a single disease; it is a term that describes a disease process," said Thomas Sinks, associate director for science, National Center for Environmental Health. That process involves an accumulation of gene mutations and other changes that occur in cells over a period of time ranging from years to decades, depending on the kind of cancer. Those mutations cause cells to proliferate out of control and develop into a tumor that invades other tissues and spreads (metastasizes) to other areas of the body.

Most of the gene mutations involved in cancer are thought to result from exposure to cancer-causing agents, or carcinogens, including chemicals, viruses, ultraviolet light, ionizing radiation, and even certain inflammatory syndromes. Inherited mutations can predispose a person to certain cancers (e.g., cancers of the breast and colon), and heredity may influence a person's innate defenses against cancer.

For every type of tissue in the body, there is a form of cancer that goes along with it, and sometimes more than one. Each of these cancer types and subtypes has a different pattern of gene mutations, is considered a different disease, and requires different treatment.

Even leukemia is categorized into many different subtypes based on the type of white cells affected and the genetic damage involved. Each subtype is itself considered to be a different disease. The cause of each subtype, which in many cases remains unknown, is also thought to be different.

Disease clusters in regional news over past 16 years:

1) Brain tumor cluster; Naperville, ILL.; 1996 (third floor of Amoco research building)	8) Cancer cluster; Hamburg, N.Y.
2) Brain cancer; Sugar Creek/ Independence, MO.; 1997	9) Brain tumors; St. Lucie County (Tampa), FLA; 1997
3) Brain tumor/leukemia; Toms River, N.J.; 1996	10) ALS (amyotropic lateral sclerosis) in three members of San Francisco 49ers football team; 1986
4) Childhood leukemia; Woburn, MASS. (water contaminated with TCE)	11) VDTs and miscarriages; California mid-state study; 1988
5) Childhood leukemia; Denver, COLO. (ELFs-extremely low frequency electromagnetic radiation, e.g., power lines)	12) Down syndrome; Pampa, TEXAS; 1986
6) Leukemia cluster; Marion, OHIO	13) Birth defects/miscarriages and microwave transmission towers; Vernon Township, N.J.; 1983
7) Birth defects; Brownsville, TEXAS; 1991	14) Cancer/birth defects, landfill; Bronx, N.Y.; 1988

Test No. 1 for a suspected cancer cluster is to look closely at the types and subtypes of cancer making up the cluster. "Each case of cancer must be carefully identified," said Randall Harris, a cancer epidemiologist with The Ohio State University's Comprehensive Cancer Center. "If more than one type is involved, it's unlikely that one specific carcinogen will be responsible."

Clusters of brain tumors often raise concerns. These cases must be examined carefully because many types of cancer metastasize to the brain. Therefore, these should be excluded from a suspected cluster of primary brain tumors, which are tumors that originate in the brain.

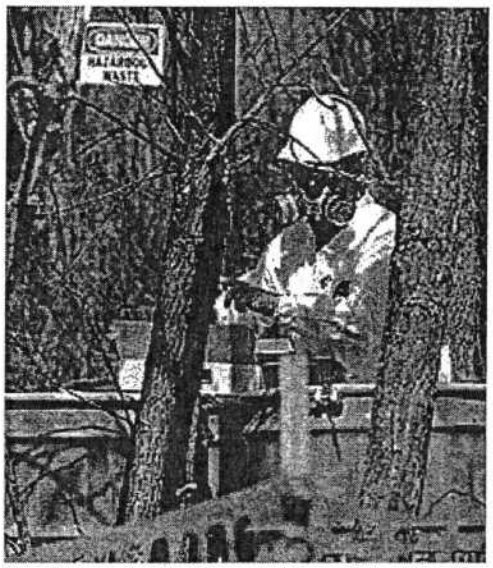
It is also essential to determine when each case in the cluster was diagnosed, said Mary Lerchen, an epidemiologist with the CDC's Cancer Surveillance Branch. "When King Hussein of Jordan died last year, many people may have thought his cancer was diagnosed in 1998. Actually, he was diagnosed in 1992; 1998 was the year in which his disease became incapacitating," she said.

If the year of diagnosis for each case is ignored, it can lead people to believe a cluster exists when, in actuality, the cases occurred over a period of 10 years or more.

"Suspected cancer clusters often fall apart when looked at closely for cancer type and diagnosis year," said Deborah Gray, a clinical associate professor in environmental health sciences at Ohio State's School of Public Health.

If the suspected cluster continues to hold up, Test No. 2 is to determine if cancer is truly present at a level statistically greater than expected, which can be determined by comparing the incidence of the malignancy in the town against its state or national incidence. Often, said Gray, "the rates are not higher than what you would expect to see in the general population."

But even when a cluster is deemed statistically significant-that is, the number of cases of a particular cancer is present at a statistically higher level-that doesn't necessarily mean that the cluster is biologically significant, said Gray.



A radiology technician working at the site of a suspected cancer cluster on property adjacent to River Valley High School outside of Marion, Ohio. The barrels, which were empty, were on hand in case contaminants were found on the site. Photo courtesy of the Marion Star.

Test No. 3 requires determining whether each case in the cluster was exposed to the same suspected carcinogen. Actually, this question requires multiple answers. For example, to develop most kinds of cancer, a person must be exposed to a carcinogen. Lung cancer, for example, is caused by smokers inhaling carcinogen-laden tobacco smoke deep into their lungs repeatedly for years at a time; skin cancer often develops when light-skinned people are exposed for long periods to the ultraviolet rays of the sun for many years.

Similarly, an epidemiologist investigating a suspected cancer cluster must show how each case was exposed to the suspected carcinogen-preferably, a carcinogen that is known to be associated with the form of cancer found in the cluster. "We not only have to identify a complete pathway of exposure for each case in the cluster," said Gray, "but we have to show that the cases could get a sufficiently high dose of the chemical for a sufficient period to actually cause cancer."

That, in turn, is made difficult by cancer's long period of development. "Cancer isn't like an infectious disease in which a person is exposed one week and becomes ill the next week," said Harris. "Many cancers take years or decades to develop." How does one reliably determine these routes and periods of exposure for each person years earlier in life? "It's very difficult," said Harris.

Cancer clusters under investigation

Ironically, cluster investigations were first begun in the early 1960s by epidemiologists with CDC who saw the study of clusters as a strategy for identifying a virus as a cause of human cancer. The idea was fueled by discoveries around that time that viruses were associated with some animal cancers and with one type of lymphoma. It was thought that cancer clusters might help find such a virus and perhaps reveal that cancer is transmissible.

Those scientists focused first on a cluster of leukemia cases at a parochial school in Niles, Ill., and between 1961 and 1982, the agency investigated 108 clusters around the U.S. As the number of

investigations grew, so did the number of factors that might explain them.

Little was gained from these studies, and research interest in cancer clusters waned. Since then, though, the public's interest has been renewed. The CDC is often involved in the investigations, but usually only when its help is requested by state health departments.

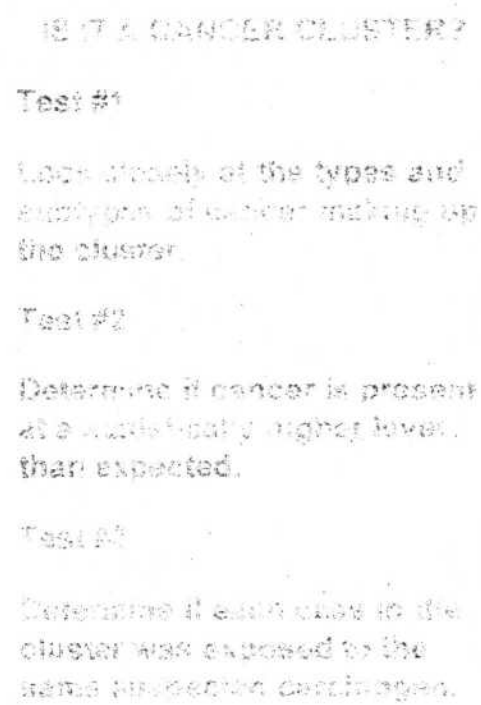
Investigations of cancer clusters generally begin with a request to the state health department. The requests generally come from citizens, physicians and nurses, and local health officials who believe they have found an unusually high level of cancer. (The National Institute for Occupational Safety and Health, or NIOSH, investigates reports of suspected cancer clusters in business or industry.)

Successful investigations

Some cancer clusters have led researchers to an identifiable cause. As these examples show, most successful investigations involve clusters of malignancies that are either extremely rare or not ordinarily seen in a particular group of people.

In 1971, for example, investigation of a cluster of vaginal cancer (specifically, clear cell adenocarcinoma) in young women-a cancer which is rarely seen in women-was traced to the use of a drug by mothers during pregnancy. The drug, diethylstilbestrol (DES), was prescribed to expectant women to treat morning sickness.

In 1974, a cluster of cases of another rare malignancy, angiosarcoma of the liver, led to the identification of vinyl chloride as a carcinogen in workers involved in the manufacture of that chemical.



A third example occurred in 1981 when alert American physicians noticed clusters of young gay men with a form of cancer that tended to occur in elderly men in the Mediterranean, together with a rare pneumonia, Pneumocystis pneumonia. The cancer was Kaposi's sarcoma, and the investigation of the cluster revealed the syndrome known as AIDS and led to the discovery of its cause, the human

immunodeficiency virus.

Another kind of successful cluster investigation involves a cancer that has a known cause. The best example of this is mesothelioma, an extremely rare cancer of the lining of the chest wall and lung surface that is almost always associated with asbestos exposure. "A case of mesothelioma causes us to immediately think asbestos," said Sinks.

Sinks described an investigation in the mid-1980s of five cases of mesothelioma in a Native American pueblo of about 2,000 in New Mexico-about 1,000 times the number of cases that would be expected.

An investigation revealed that silversmiths in the pueblo used asbestos mats to protect their worktables from the heat of brazing torches and molten metal. The workers cleaned the mats by rubbing them together, which produced a fine cloud of asbestos fibers.

In addition, members of the pueblo whitened deerskin leggings and moccasins used for traditional dances by rubbing them with cakes of asbestos. When clumps of asbestos began to form, the individuals held up the leggings and slapped them, dispensing asbestos fibers in the air. The pueblo's source of asbestos was discarded steam-pipe insulation.

"This cluster involved only five cases," said Sinks, "but the disease is so rare and the cause so well known that even this small number was striking."

Usually, though, small numbers pose big problems when investigating a cancer cluster in a community, and such an investigation has never ended with the kind of success described above. The cancer cluster in Marion, Ohio, for example, involved six verified cases of cancer during a 23-year period when only two were expected.

Working with such small numbers of expected cancer cases and such a small number of excess cases makes it very difficult to determine what is really happening, said Lerchen. "You don't know if what you consider to be an excess is just a blip due to random variation, or whether it truly is a significant increase."

In fact, it's even difficult to determine what constitutes a cluster.

"There is no real definition of a cluster," said Robert Indian, chief, Chronic and Environmental Disease Surveillance, Ohio Department of Health. "There is no consensus on how many cases it takes over what period of time and in what geographic area."

The emotional toll

Because cancer clusters involve so many difficulties, vagaries, and unknowns, it's not surprising that the results of cluster investigations can be inconclusive at best. Meanwhile, citizens in the community are hungry for the experts to link their disease to a cause that may not be there.

"Epidemiologists get caught in the middle," said Lerchen. "The public wants a definitive answer and may think we are hiding something when actually the numbers just aren't there."

Sometimes a study of cancer rates requested by the community produces nothing unusual or produces findings that are not well received, said Gray. "Often the cancer rates turn out to be about what we

expect. On occasion, we find some kind of a statistical elevation in rate, but very frequently the types of cancer we would find elevated will be lung cancer, which has well-known risk factors."

Some people don't accept this information well, she said, "particularly people who have already formed an opinion about the cause of their illness. So it's very unsatisfying for everybody."

To minimize that dissatisfaction, it's important for people in public health to explain at the outset of an investigation what can and cannot be done in terms of finding the cause of their illnesses, she said.

"It's important for people to understand that even though we use the best scientific methods to shed light on what is going on in a perceived cluster of diseases, we may not be able to explain the cause of everyone's illness. At best, we may find some clues about a few of the cases. Unless you have a situation like an occupational setting, where there is a commonality of exposures, it's very hard to find an association with one particular cause."

At the same time, Gray said, "we can't prove a negative; we can't prove that the contaminated property, for example, didn't cause their disease. All we can do is look for biologically plausible associations. We can also provide evidence from public health practice and from the scientific and medical literature that a particular exposure has never been known to cause a particular disease in people or experimental animals.

"There will be people in the community who accept that, and there will be those who already have their minds made up and say you've been bought off."

In the end, she said, people should realize that upon close examination, perceived clusters often dissipate. "It's very unusual to have a cluster that is significantly higher than the expected rate. And even then, people need to be prepared for the possibility that it is not a biologically significant association. It could be pure chance."

In spite of the difficulties, though, cancer clusters need to be investigated, said Indian. "We can't simply say those five cases of brain cancer are just a coincidence and walk away from it; that doesn't help anyone."

In fact, he views such calls for help from a community as an opportunity. "We tell people the number of cases we'd expect to see, what we know about different kinds of cancer, and provide them with information on cancer prevention."

The cluster at Marion also shows the importance of a cancer registry, which is useful for determining the amount of cancer that people can expect to see based on state and county history.

"No one can rule out the possibility that a cluster of a certain type might be related to an environmental pollutant," said Harris, "but it's very difficult to prove it. That's not comforting to the people of a community fearful of cancer, but I think that the information should be given to people because the understanding may perhaps eliminate some of the difficulties. I'd like people to understand that cancer takes many different forms, that each form has different risk factors, and that they often involve a combination of risk factors.

"It's like heart disease. Heart disease has many risk factors: smoking, hypertension, diabetes, high salt in the diet, obesity, and stress. Many factors can contribute to a heart attack. Cancer is no different."

Public health officials can help communities concerned about cancer clusters without spending much money, said Sinks. This includes providing education and information and being responsive.

Thinking of a cluster in terms of an investigation, on the other hand, raises an important problem. "Frequently, when one starts to phrase this as a research issue, the community has expectations that something will be found that may not be there," he said.

"What can be difficult is to listen to the community and hear what people are really asking. People may come to an epidemiologist, to someone in academia or public health and say, 'We think we have too much cancer, and we want you to find out why and correct it.' The epidemiologist may then ask a series of questions to investigate whether there really is too much. Ultimately, though, the question really being asked is: 'Is it safe; is it safe for my children.'"

And that, of course, is why it will always be important to address concerns about cancer clusters.

Darrell Ward is a senior medical writer in the Office of University Communications.

Return to Frontiers table of contents.

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Cancer Cluster or Coincidence?

Author:
Published on: **March 13, 2001**

Situated near the boundary of Vermilion and Lafayette parishes in south Louisiana, the small rural community of Indian Bayou has local television and newspaper media attention focused on a big problem. Residents there suspect they may be in the midst of a "cancer cluster" in an area too sparsely populated to even have its own zipcode. They've organized committees to document information and seek solutions from health and environmental agencies. Their plight has a deja-vu quality because another Acadiana community, Coteau, experienced a similar situation in 1996 and no conclusive findings have yet been determined.

Through discussions at cancer support groups meeting monthly at the local Methodist church, Indian Bayou residents noticed an unusually high incidence rate of the disease among their families and neighbors. An informal investigation revealed 57 cases, resulting in 30 deaths so far, within a five-mile radius area in the past twenty years. These numbers are particularly alarming because the the average incidence rate for the Acadiana region is about 250 cases per 100,000 persons.

Early in 2001, concerned citizens have launched an intensive grassroots effort to find out why their community has been hit so hard by the dreaded disease and what can be done to remedy the problem. For many whose own well water does not smell or taste good, the most obvious possible cause is groundwater contamination from an oilfield waste injection well in the area. The suspected culprit supposedly disposes only non-toxic saltwater by deep injection into the soil, but there is skepticism in the community since the operating company has a questionable history of regulatory and environmental violations. Even if the injection well is not directly responsible for contamination of groundwater, it may be involved by default because of its location. A recent report indicates the injection well is on the same site where a known hazardous waste disposal pit was operated during the early 1980's when environmental restrictions were still notoriously lax in Louisiana. Thus, it is not improbable that gradual seepage of harmful chemicals from the abandoned pit was accelerated by the pressurized injection of saltwater in recent years. The people of Indian Bayou have enlisted the help of local, state, and federal authorities to verify or negate their suspicions.

For too many years, a shamefully large number of Louisiana officials have neglected the state's environmental health issues in favor of the lucrative petrochemical industries. Indeed, the stretch of polluted land along the Mississippi River from Baton Rouge to New Orleans was dubiously dubbed

as "Cancer Alley" decades ago. Fortunately, and hopefully not too late, the political trend of environmental irresponsibility has slowly changed in the state. With money designated by the EPA's Superfund, the most easily identifiable problem sites of hazardous waste disposal have been "cleaned up." Stricter regulations with stiffer penalties are being enforced more consistently against violaters of anti-pollution laws.

With tenacity and hard work, concerned members of Acadiana communities like Indian Bayou have increased public awareness about potential chemical dangers in their neighborhoods. It has become more difficult, and sometimes impossible, for waste-disposal companies to obtain new permits because of more voluble citizen input at public hearings. While municipalities strive to extend the safety of district waterworks lines to outlying communities, many rural homeowners purchase bottled supplies. Although the definitive link between "cancer cluster" syndromes and groundwater contamination has not yet been firmly established, groups have become pro-active in protecting their health and environment. People in south Louisiana, particularly the Cajuns, will no longer tolerate their backyards being used as chemical dumping grounds.

Title: Why community ***cancer clusters*** are often ignored.
Subject(s): CANCER -- Epidemiology
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Author(s): Kase, Lori Miller
Abstract: Discusses community ***cancer clusters***. Significance; Mapping breast ***cancer*** cases in West Islip in Long Island, New York; ***Cancer clusters*** as a vehicle for identifying ***cancer***-causing agents.
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WHY COMMUNITY CANCER CLUSTERS ARE OFTEN IGNORED

The 10-foot-long map of Lorraine Pace's Long Island community of West Islip is spread out on her dining-room table. Pace, a 55-year-old breast cancer survivor and the 20th of her neighbors to be diagnosed with the disease, points out patches of yellow-highlighted squares scattered across the map. "These are the breast cancer cases," she explains. Within days of undergoing a lumpectomy in 1992, Pace had galvanized some of the women represented by these squares, and the group--the West Islip Breast Cancer Coalition--spent the next year and a half mapping breast cancer cases in an effort to pinpoint "hot spots" of the disease. They hoped these spots could be correlated with potential environmental threats--and their illness linked to a cause.

At first glance, such community cancer clusters would appear to be the perfect vehicle for identifying cancer-causing agents: by tracing factors to which all the individuals were exposed, investigators should in theory be able to spot a culprit. And the public certainly views clusters that way. State health departments in the U.S. received about 1,500 requests for cancer cluster investigations in 1989, according to a survey by Daniel Wartenberg of the Robert Wood Johnson Medical School in New Jersey, and that number has continued to increase.

But most cancer clusters appear to happen by chance. It is largely for this reason that health officials these days are usually reluctant to investigate reports of localized excesses in cancer incidence--even the Centers for Disease Control and Prevention gave up routinely investigating cancer clusters in 1990 because they required such intensive resources and yielded so little information in return.

Indeed, although several known carcinogens have been discovered through occupational or medical clusters (for instance, vinyl chloride's link to angiosarcoma in workers who make polyvinyl chloride or the connection of diethylstilbestrol, or DES, to gynecologic cancers in daughters of women who took the drug during pregnancy), only one community cancer cluster has ever been traced to an environmental cause. In that case, researchers linked an epidemic of a rare respiratory cancer called mesothelioma in a Turkish village to an asbestoslike mineral, erionite, that was abundant in the soil.

Among the reasons for which health officials may discount a community's suspicion of common cause is that local groups often lump together different types of cancers (which are unlikely to be triggered by the same carcinogen). These citizens tend to include cases that were diagnosed before the afflicted individuals moved into the neighborhood, or they conduct what the epidemiologist Robert W. Miller of the National Cancer Institute calls epidemiologic gerrymandering: "They find the cases, draw boundaries around the cases, and say, 'Aha, we've found a cluster.'"

Even when such assemblages are ruled out, most clustered cases that initially appear to be statistically significant turn out to be simply naturally occurring spikes in cancer incidence. According to Raymond R. Neutra of the California Department of Health Services, probability theory suggests that 17 percent of the 29,000 towns or census tracts in the U.S. will have at least one of the 80 recognized types of cancer

elevated in any given decade, producing 4,930 chance clusters. This high false positive rate is further compounded by the problem of statistical legitimacy--most reported cancer clusters are too small (often fewer than 10 cases) to be judged conclusively.

Even when there is a potential cause in the environment--and a biologically plausible hypothesis of how it might contribute to cancer--trying to trace cancer cases to a specific cause still poses unique challenges. "Cancer cases are clinically nonspecific--you can't look at a leukemia case clinically and say, 'Ah, this is radiation-caused leukemia,'" explains Clark. W. Heath of the American Cancer Society. This problem is exacerbated by cancer's latency. Unlike outbreaks of infectious diseases, which can be linked to some recent exposure, a cluster of cancer cases might have its roots in an exposure that occurred 10 to 20 years earlier.

"Reconstructing a person's exposure history is a tremendous scientific challenge," says G. Iris Obrams of the NCI. "For one thing, none of us can reliably recall all the things we've been exposed to. And the further back we go, the more uncertain we are about the accuracy of exposure information and the more likely it is that measurement techniques have changed as well." Obrams also notes that one has to take into account many known cancer risk factors when trying to assess the impact of environmental agents, in part because the disease may be triggered by a combination of environmental, genetic and other factors.

In conducting its own crude version of a cancer cluster investigation, the West Islip Breast Cancer Coalition could never have overcome all these obstacles. But together with many other reports of breast cancer clusters on Long Island, the West Islip situation managed to point epidemiologists in the right direction. Subsequent studies revealed that Long Island did indeed have higher than expected rates of breast cancer incidence and mortality and was, in fact, part of a broad breast cancer cluster extending all the way to Philadelphia. They also helped to establish Long Island as the setting for the largest epidemiologic study ever to be conducted on the link between environmental contaminants and breast cancer.

"We tend to move beyond cluster analysis as quickly as we can," says Obrams, explaining public health officials' decision not to follow up on every reported cluster in Long Island. "We get whatever information we can about clusters to see if there is any lead that we can develop for scientific study, but we know we can get more conclusive data from a larger, well-designed scientific project."

PHOTO (COLOR): LORRAINE PACE mapped a Long Island breast cancer cluster.

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By Lori Miller Kase

Lori Miller Kase is a science and health writer based in Virginia.

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THE BRAIN TUMOR SOCIETY

Q & A: Cancer Clusters

by Roberta D. Calhoun, ACSW, LICSW

Q: Several people in my neighborhood have been diagnosed with cancer, and I am very concerned about what this may mean. Who will look into this for me?

A: Local and state health departments accept requests to evaluate cancer clusters, where several similar cancers seem to occur in a local area over a short period of time.

Scientists known as Epidemiologists must consider many factors when evaluating possible clusters. These include:

- **Background risk:** Cancer is so common that over time, it will affect almost three out of four families. It is not unusual for an apparently large number of people in a workplace or community to develop cancer. In fact, requests to evaluate possible clusters are received in the U.S. nearly every day. Epidemiologists ask: Is the observed local rate *greater* than this known high background incidence? If so, further studies may be conducted to explore possible causes.
- **Narrow focus:** There are over 100 different types of brain tumors, and "cancer" represents over 100 diseases. Researchers believe these different diagnoses have differing causes. "True" cancer clusters represent a high incidence of *medically similar diagnoses* in a small area. (Benign and malignant tumors are not typically evaluated together.) Clusters of rare tumors are also viewed as more likely to represent true clusters, with possible links to local risk factors.
- **Size of the population:** Many cancer clusters contain such a small number of cases that it is hard to draw meaningful conclusions from statistical analyses. The most productive scientific studies require large sample sizes (usually at least a few hundred). This situation puts most cluster studies at a disadvantage.
- **Community profile:** Demographic variables, such as age, must be examined as part of any cancer cluster investigation. Cancer risk increases with age; a community with more older residents than average may also have a higher incidence of cancer.
- **The role of chance:** Apparent cancer clusters are surprisingly common. In a random distribution of cancer cases, neighborhood rates of illness will vary naturally, and some clustering will occur by chance. The vast majority of apparent clusters are actually found to occur by chance. Investigators ask: Is the incidence seen in this community sufficiently high that its having occurred by chance can be ruled out?

True clusters are so rare that fewer than five percent of investigations result in further epidemiologic study. (A *case-control study* is typically the method used to explore possible causes in the area. To date, however, few of these studies have identified the cause of a particular cancer.) One recent cluster

evaluation which produced statistically significant findings has proceeded to a case-control study; it involves childhood brain tumors. This example, outlined below, illustrates the skilled community advocacy, political support, and investment of time and money often needed to pursue cluster investigations.

Timeline: The Toms River (Dover Township, Ocean County, NJ) Childhood Cancer Cluster Investigation.

1979: Michael Gillick is born in Ocean County, NJ, and three months later is diagnosed with neuroblastoma, a rare cancer of the sympathetic nervous system.

1982-1984: Ciba-Geigy, which manufactured dyes and plastic additives in Dover Township (Ocean County, NJ) from 1952-1977, is placed on the Superfund list after the Environmental Protection Agency detects cancer-causing chemicals at the company's Dover site. In April, 1984, Ciba-Geigy's ocean discharge pipeline leaks in the area. Treated chemical effluent seeps under roads and forms a sinkhole at an intersection which in the 1990's is regarded as the center of a childhood cancer cluster.

1989: Michael Gillick's mother Linda forms a charity named *Ocean of Love,* which serves families coping with pediatric cancer. The high number of clients requesting the agency's services underlines local concerns about cancer incidence.

1995: A nurse at Children's Hospital of Philadelphia notes an unusual number of cancer cases from Ocean County, NJ. She contacts the NJ Health Department to request a summary of the county's childhood cancer statistics by age and town.

March-April, 1996: *The Newark Star Ledger* breaks a story about nine-month-old NJ State Health Department statistics from August, 1995, suggesting the rate of childhood brain/ CNS cancer between 1979-1991 in Toms River was three times higher than state and national averages. For Toms River children under five, the rate was *seven times* higher than expected. Overall childhood cancer rates in Ocean County were seven per cent higher than expected. Parents plan a rally at the county Health Department; about 100 meet with officials, who promise to press state and federal agencies to study local cancer incidence. They acknowledge the state cancer registry is backlogged by up to seven years, and the state's report, containing four to five-year-old data, excludes children treated out-of-state. Linda Gillick appeals to a local Congressman to fund research. Legislation is introduced to set aside $400,000 for research and for an improved cancer registry.

At a pivotal town meeting attended by 1200 citizens, state health officials and the Agency for Toxic Substances and Disease Registry (ATSDR) prepare to respond. For 90 minutes area residents, including 17 year old Michael Gillick, refuse to let them speak, emphasizing their loss of confidence in local government. Officials propose a citizens' advisory committee to serve as liaison with various agencies and to help determine a plan. A Congressman asks the U.S. Department of Health and Human Services to match state funds for a study. The County Board of Health and Board of Chosen Freeholders pledge $250,000 to research the problem. Due to a history of water contamination in the area, water sampling resumes to search for possible causes. Investigators purposefully design this search to include nearly three times the chemicals normally monitored in drinking water.

The Citizens Action Committee on Childhood Cancer Cluster, chaired by Linda Gillick, meets to help shape the public health response plan for a state investigation. This plan will map out the extent of research, review possible exposure pathways, create study timelines and establish plans to publicize results. During water sampling, elevated levels of radiation in area wells are detected. United Water Toms River also detects increased levels of trichloroethylene, described as a "probable human carcinogen."

May-November, 1996: Fragments of molecules associated with acrylonitrile, known to produce brain cancer in laboratory animals, are found in Toms River wells. (Acrylonitrile was detected at one Dover Township Superfund site.) A Congressman testifies to increase funds to the ATSDR, which is paying for most of the study; the House approves $900,000. Because the ability to confirm or dismiss the suspected cluster requires current data, congress is approached for funds to eliminate the registry's backlog. The Governor signs a bill to set aside $400,000 to update the registry and fund an epidemiologist to analyze data and identify trends. She dedicates $200,000 from a discretionary fund to test township water. During this period, residents complain that salespersons representing private companies are exploiting the community's fears by offering water sampling analysis for profit. By September, the Toms River Park Childhood Cancer Memorial, which lists names of area children lost to cancer, is nearly out of space.

December, 1996: The updating of the state cancer registry is now complete: The number of childhood cancer cases in Ocean County is notably *higher* than reported in 1995. The NJ health department and ATSDR begin a "massive" twelve month epidemiological analysis to determine which of the pediatric cancers show statistically significant increases.

January-October, 1997: A NJ Senator seeks $1 million to continue the study. Citing suspected links between contaminated water and cancer levels, health officials plan an extensive computer model of the municipal water system to determine probable rates of exposure. Congressmen seek $5 million for a case-control study (a comprehensive epidemiological investigation) to explore causes. A subcommittee of the House Appropriations Committee provides an initial $2 million to further the investigation.

December, 1997-present: Incidence analyses confirm several of the elevated cancer rates are statistically significant. That is, the rates are sufficiently higher than the "naturally-occurring" background rate that it could be concluded that the local cluster was not a chance occurrence. Some results: For Dover Township in 1979-1991, all cancers combined were elevated significantly, and the cancer incidence in girls under 5 was nearly double the expected rate. In Toms River, all cancers combined were significantly higher than expected. Brain/ CNS cancer was significantly elevated in children under 5 and in girls under 5. Children under 5 were found to have significant elevations of astrocytoma. The ATSDR proceeds with a case-control study to identify possible risk factors. Extensive family interviews are completed during the fall of 1998, and analyses are ongoing.

NOTE: *For updates and a map of cases, see www.app.com/doc2/cancer (The Asbury Park Press). This report is dedicated to Ms. Calhoun's 9 year old cousin Peter K. of Toms River, NJ, who died of lymphoma ten years prior to the period under study.*

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Public Requests for Cancer Cluster Investigations: A Survey of State Health Departments

Craig W. Trumbo, PhD

A B S T R A C T

Objectives. This study examined the frequency of requests that state health departments investigate cancer clusters, the nature of those requests, and the resources available for the investigations.

Methods. A mail survey was sent to state health departments requesting data for 1997.

Results. Approximately 1100 cluster investigation requests were made in 1997. Most requests were made by citizens, and no pattern emerged for types of cancer or hazards suspected. States rate this work as average in importance and feel satisfied with the successfulness of their communication efforts.

Conclusions. Few cluster inquiries require further investigation. Nonetheless, this interaction represents resources well spent in terms of public service and education. (*Am J Public Health.* 2000; 90:1300–1302)

State health departments often serve as the resource of first choice for a citizenry ever more concerned about the incidence of cancer. Citizen alarm specifically over cancer clusters has reached such a level that, according to a story in the *New York Times*,[1] this "public clamor" is influencing the nature of basic research being conducted on cancer. Other articles have appeared recently in the national press describing "the cancer cluster myth."[2] A casual search of any general news database (e.g., Lexis/Nexis) reveals that the term *cancer cluster* has become part of the popular lexicon.[3–5]

What is the nature of this phenomenon? In 1989, state health departments in the United States received a total of 1300 to 1650 requests to investigate suspected cancer clusters.[6] Examinations of how these investigations were done have included a review of work done at the Centers for Disease Control and Prevention (CDC)[7] and evaluations of state epidemiologic and communication protocols.[6,8–10] The raw increase in cancer in an aging population and the phenomenon of the "random cluster" are certainly associated with the frequency of citizen complaints over cancer rates.[11,12] Other factors, such as increased environmental awareness,[13,14] disclosures of hazardous waste sites,[15] and media attention to cancer, are probably implicated as well.[6]

This report, which is part of a larger study of the social psychology of cancer clusters,[16–21] updates previous studies examining the frequency of requests for cluster investigations and the nature of state responses. It also provides information on 3 unexamined aspects of cluster investigations: the complainants, the cancers of concern, and the perceived hazards. Additionally, it evaluates the occurrence of citizen involvement in these investigations—what has been termed "popular epidemiology."[14,22–26]

Methods

Health departments were surveyed by mail, according to standard procedures, in early 1998.[27] Instructions emphasized that the survey was about cancer clusters, not disease clusters generally. Only Ohio refused to participate. In addition to asking general questions, the survey asked for specific details about all cluster investigation requests made in 1997. States were required to access records to provide this information; 29 states were able to comply. In total, 428 cluster cases were detailed (40% of the total). Although these data are incomplete, they can at least provide some insight into the experiences of many state health departments.

Results

Results involving the number of complaints and the characteristics of state health department reactions are presented in Table 1 (a supplementary table with a state-by-state breakdown is available from the author). A few additional notes on these results are made here, as well as a report of the detailed examination of the 428 cases.

Number of Complaints

Five states were not able to provide information on the number of complaints made. If these missing data are estimated by median substitution (eliminating California's undue influence), a fair estimate for the national total is approximately 1100 (close to the 1989 figure). Concerning the perceived increase, a few respondents wrote comments indicating that while the number of complaints was not up dramatically, the intensity of community concern in these cases has increased.

State Responses

Regarding the nature of state responses, in addition to the averages reported in Table 1, correlations were made among the last 7 variables listed in the table. Two are worth noting. Previous research showed a positive correlation between states' having resources available for cluster investigations and the number of investigations made.[10] This still holds true, with a correlation of 0.42 ($P<.05$) between the number of requests made in 1997 and the level of personnel resources available. The number of requests made in 1997 is also correlated with

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This brief was accepted November 15, 1999.

TABLE 1—Number of Public Requests for Cancer Cluster Investigations and Characteristics of State Health Department Reactions to Requests

States conducting cluster investigations, %	93
States with standing response protocol, %	67
States regularly issuing reports on cancer rates, %	67
States that have ever formally evaluated communication of cluster information	2 (Missouri and Wisconsin)
No. of Persons available for cluster investigations (on average)	<0.25 (57%) 0.5–1 (32%) >1 (10%)
Importance of cluster investigations relative to other tasks (1 = unimportant, 7 = important)	Average (mean = 3.5)
Perceived satisfaction of complaints (1 = satisfied, 7 = unsatisfied)	Average (mean = 3.5)
Complaints satisfied at first contact (via phone), %	75 (mean = 65, median = 75)
Total investigation requests from the public in 1997	1024 (mean = 22, state median = 9)
Perceived increase/decrease of complaints (1 = decrease, 7 = increasing).	Perception of slight increase (mean = 4.6)
Complaints associated with legal action, %	<5

the ranking of the importance of this work (0.30 [$P = .05$]).

Popular Epidemiology

Overall, the results do not indicate that popular epidemiology is widespread. States reported that most investigation requests (83%) were motivated by general or informal feelings about cancer rates, and that the requesting party presented data, expert consultation, statistical analysis, or mapping in only about 3% of cases. Also, states did not report that many of their investigation requests were associated with cases involving legal action, with half of the respondents indicating they saw no such cases in 1997. However, 10 states did indicate that at least 10% of that year's investigations were linked to lawsuits.

Sources of Investigation Requests

In 65% of the 428 cases on which detailed information was provided, investigation requests came directly from citizens. About 10% of the cases involved a local health agency, with the balance distributed among the other categories (physicians, news media, federal or state agencies, elected officials, others). Although often very involved in covering cluster investigations, the news media were direct participants in the initiation of cluster investigations in only 3% of the cases reported.

Cancers of Concern

Again drawing on the 428 detailed cases, results show that the average number of cancer locations specified in investigation requests was just under 2—ranging from only 1 site (specified by 65%) to 5 or more (specified by 6%). In terms of the specific cancers of concern, 30% of requests were based on nonspecific cancer concerns ("various cancers"). Leading the list of specific cancer concerns were breast cancer (26%), leukemia (18%), brain cancer (17%), and lung cancer (15%). Cancers of the male and female reproductive organs, colon cancer, and pancreatic cancer each showed up in 5% to 9% of the investigation requests.

Perceived Hazards

A categorization scheme was developed for the range of perceived hazards. The coding scheme included the following: none specified, multiple hazards, radiation (from uranium mining, power plants, research facilities), agricultural chemicals (herbicides, nitrates, pesticides, DDT, chemicals from golf course and lawn care spraying), industry (contaminants from Superfund sites, landfills, mining, and dumps; dioxin; chlorine; polychlorinated biphenyls [PCBs] and other emissions if not specified as water or indoor air pollution), travel (auto emissions, benzene, methyl tertiary butyl ether [MTBE], emissions from airports and road construction), indoor air (including radon and asbestos), and contaminated water.

The largest single category was "none specified," with 40% of requests not specifying a possible causal mechanism. A direct concern over some industrial situation accounted for 21% of the requests; water and multiple causes for about 8% each; other, indoor air, and agricultural pollution for about 7% each; radiation for 3%; and travel for 2%.

Discussion

Despite perceptions to the contrary, the rate of requests for cluster investigations in 1997 had not changed appreciably compared with 1989. It is possible that 1989 was an unusual year, followed by a reduction and a subsequent increase in requests. In any case, the number of such requests should be tracked.

With respect to the public's perception, these results paint a picture of citizens holding a fairly generalized concern about cancer rates, usually without specifically identified cancers or hazards (although some notable exceptions can be found). Although the data reported here show no relationship between the public's perception of specific cancers and its perception of potential causes, the possibility that such a relationship exists has been ignored in research and should be reexamined. Further, although popular depictions of salient cases (such as in Woburn, Mass, where citizens conducted their own investigation of industrial contamination of drinking water[28]) could lead one to think otherwise, activity that could be termed "popular epidemiology" is fairly uncommon. In most cases, citizens and others who approach their health departments for answers about cancer rates do not marshal their own evidence or analysis. And although legal action associated with cluster investigations is uncommon, it may be on the increase in some states. This bears watching.

Of the more than 1000 complaints about cancer rates that are received by state health departments every year, very few are determined to require significant investigation. Because of the imperfection of epidemiologic tools and data, the nature of the disease, and other factors, clusters are rarely identified. Still, the interaction that state health departments have with communities over suspected clusters represents resources well spent in terms of public service and education. Further, these cases have contributed to the establishment of state cancer registries and have helped make these archives active participants in cancer surveillance and control. □

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NDCA
National Disease Clusters Alliance

The Honorable Barbara Boxer
US Senate
112 Senate Hart Building
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March 1, 2011

Dear Senator Boxer,

I am writing to express the National Disease Cluster Alliance's enthusiastic support for your bill to strengthen protections for children and communities from disease clusters.

Currently, chronic diseases like cancer, birth defects, and multiple sclerosis strike over 100 million men, women and children, accounting for more than a third of the U.S. population. These diseases are responsible for seven out of ten deaths in the United States.

Around the country—from the Acreage, Florida to Kettleman City, California to Fort LeJeune, North Carolina—communities are faced with unusually high rates of disease, or in other words, disease "clusters," and health officials are unable to determine why. Questions abound about what is causing these elevated rates. Is there something in the drinking water? Does the nearby military institution impact our health? Is the air we breathe causing us to get sick? Too often questions posed to local health officials are not answered satisfactorily or not even responded to at all.

Although over 1000 concerned residents request investigations into suspected disease clusters every year, cluster investigations are rarely undertaken by government agencies. When it comes to tackling infectious disease, public health institutions perform well, but they do not have the same ability to identify and respond to environmentally-related illnesses. Health officials are currently working with their hands tied as they don't have the resources or time to address the concerns. This results in tremendous frustration for concerned community members and a significant loss of trust in government. Your bill will increase federal and state capacity to answer questions about disease clusters asked by concerned community members.

While no community is immune from a potential disease cluster, residents of low-income and racial minority communities are at disproportionate risk for exposure to environmental hazards, and potential disease clusters. Your bill will create safer and

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NDCA
National Disease Clusters Alliance

healthier communities across the nation, by identifying communities at risk and halting emerging disease clusters.

We are also delighted by your commitment to community based participatory research. There is true vision in creating a solution in which government, science and community work as equal partners in responding to disease cluster inquiries.

This bill will provide more research into causation and prevention of disease. By investigating the environment in areas with health impacts, we have the opportunity to address significant weaknesses that presently exist in the investigation of possible disease clusters. Bringing environmental agencies to the table will support the ongoing work of health agencies and add important scientific expertise to these investigations.

A strength of this bill is that it includes access to laboratories to conduct biomonitoring and environmental analysis to measure contaminants in people's bodies as well as in air, water, food, and soil. This lack of data is the weak link in current risk assessment and environmental exposure analysis. Communities currently lack access to technical assistance and this bill corrects that.

Transparency and governmental accountability are overarching goals of this legislation and have the potential to make agencies more proactive rather than reactive.

There is now an urgent need to identify and respond to emerging disease clusters in communities, and fortunately, your bill will revolutionize the experience of communities facing disease clusters.

Sincerely yours,

Terry Nordbrock, MPH
Executive Director

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About NDCA

Terry on May 9th 2011

The **National Disease Clusters Alliance (NDCA)** was formed in 2005 out of the urgent need to identify and respond to emerging disease clusters. NDCA is a group of scientists, public health professionals, and community activists joined together to help communities facing disease clusters. Currently, there are no government agencies that either track or respond sufficiently to disease clusters in communities.

Definitions: according to the Centers for Disease Control and Prevention (CDC)
A *disease cluster* is a greater-than-expected number of cases of disease that occurs within a group of people in a geographic area over a defined period of time.

A *disease cluster investigation* is a review of an unusual number, real or perceived, of health events (for example, reports of cancer) grouped together in time and location.

Need for Action

Community concerns regarding environmentally related disease clusters, such as clusters of cancers, childhood leukemia, ALS, MS, lupus, autism, and other rare diseases, continue to be major public health issues. When disease clusters occur or are suspected by members of a community, community members usually lack the resources, knowledge, skills or funding to identify and resolve the disease clusters. Governmental responses to disease clusters in locations as diverse as Fallon, Nevada, Sierra Vista, Arizona and Sacramento, California have been perceived by impacted communities as insufficient, which often leaves communities frustrated by a perceived lack of responsiveness by governmental entities. Finally, government agencies and communities alike often feel as though they did not achieve the desired results. These horrific health crisis remain unresolved and incomplete with illness and disease continuing on.

NDCA mentioned as solution in major report:

Adequacy of State Capacity to Address Noncommunicable Disease (NCC) "Clusters" in the Era of Environmental Public Health Tracking (2007) A Johns Hopkins University study published in the *American Journal of Public Health* Volume 97, Number S1. 7 pages.

The 2007 Hopkins study surveyed 50 state departments of health and concluded:

- Clusters are of key concern to communities, yet state-level capacity to address clusters was inconsistent and disjointed.
- Across states, there was no consistent identifiable individual or agency division responsible for addressing disease cluster reports.
- States were hampered by dedicated lack of personnel to address suspected or reported disease clusters, resources, and prescribed protocols, as well as inadequate interagency communication.
- Of the 50 states polled only 15 states have protocols for reporting suspected non-communicable disease clusters to the state health agency, 16 states have protocols for responding to suspected disease clusters and 8 states have protocols for communicating with the public regarding suspected disease clusters.

You Can Help

Contact us to find out more about solving existing problems with disease clusters. We seek volunteers, donors, scientific advisors, organizational advisors, cluster advocates and more.

Stop disease clusters. Protect people. Control toxic chemicals.

Health Alert: Cancer Clusters, Disease, and the need to Protect People from Toxic Chemicals

An unusually large number of people sickened by a disease in a certain place and time is known as a 'disease cluster'. Clusters of cancer, birth defects, and other chronic illnesses have sometimes been linked to chemicals or other toxic pollutants in local communities, although these links can be controversial. There is a need for better documentation and investigation of disease clusters to identify and address possible causes. Meanwhile, toxic chemicals should be identified and controlled through reform of the Toxic Substances Control Act, so these chemicals don't pollute communities and sicken people.

Due to a lack of resources, the limited statistical power in doing investigations of small communities or rare diseases, and a lack of knowledge about exposures, it has been difficult for state and federal agencies to shed light on most disease clusters and their causes. There is a need for better documentation and investigation of disease clusters and their causes. Senators Barbara Boxer (D-CA) and Michael Crapo (R-ID), have introduced legislation that would address at least some of these problems, by ensuring that the Environmental Protection Agency and other federal agencies can, and will, provide the resources necessary for investigations and other support, where state-level expertise or resources are not available.

In the United States, the Toxic Substances Control Act (TSCA) is the primary law that ensures the safety of industrial chemicals used in commercial and consumer products by regulating their use, from manufacturing to eventual disposal. Unfortunately, because of major flaws in the law the regulation of toxic chemicals in the United States has been a failure. As a result, dangerous chemicals, including those known to cause cancer, birth defects, and learning and developmental disabilities are still used widely with few, if any, restrictions. These include many of the chemicals which have been linked to some disease clusters, including TCE, dioxins, and asbestos. Better testing and regulation of the thousands of toxic chemicals

that can come into our homes, our workplaces and our schools is critical for reducing the cancer and other chronic illnesses and disease that affect our communities.

An issue paper about disease clusters in particular states was developed by the Natural Resources Defense Council and the National Disease Cluster Alliance to inform people about disease clusters affecting communities across the country. All of these disease clusters have been confirmed or are currently undergoing an official investigation, though in most cases the cause of the cluster is unknown.

The disease clusters spotlighted in the factsheet series illustrate the need for:

1. Directing and funding federal agencies to swiftly assist state and local officials, and investigate community concerns about potential disease clusters and their causes;

2. Reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements; and

3. Requiring chemical manufacturers to ensure the safety of their products.

Methods

Thirteen states, Texas, California, Michigan, North Carolina, Pennsylvania, Florida, Ohio, Delaware, Louisiana, Montana, Tennessee, Missouri, and Arkansas, were chosen for analysis based on the occurrence of known clusters in the state, geographic diversity, or community concerns about a disease cluster in their area. From May 2010 to July 2010, clusters in each state were identified by searching the websites Google, Proquest, Pubmed, and Web of Science using the name of the state and the words "cluster", "cancer cluster", or "birth defects cluster" as search terms.

The criteria for inclusion in the search were:

1. The clusters occurred after 1976, when TSCA legislation was initially passed and was intended to regulate toxic chemicals.

2. The cluster was confirmed or is currently being investigated by a federal, state or local government agency. Clusters were also included if they were identified by academic researchers and published in a peer-reviewed journal. Sources for each of the described clusters are available on NRDC's website.

When possible, contaminants discussed in investigations and news reports are identified, though in most cases no definitive cause for the cluster has been identified. In addition, industries, hazardous waste sites, or other locations which were identified by community members as being of concern are also referenced in the cluster description.

All the fact sheets were externally peer-reviewed by scientists and community members in the National Disease Clusters Alliance.

Clusters

Terry on Mar 6th 2011

Disease Cluster and Hotspot Map

Click on a dot to see information about that cluster, or scroll down to find information about all these clusters, arranged alphabetically by state.

Material on this page was originally developed by the Trust for America's Health and is reprinted here with permission. Ongoing updates are done by NDCA.

Background

The Centers for Disease Control and Prevention (CDC) define a cluster investigation as, "a review of an unusual number, real or perceived, of health events (for example, reports of cancer) grouped together in time and location." Cluster investigations seek to confirm cases of the disease; establish whether the reported cases represent an unusually high occurrence of the disease; and explore potential causes when possible.[1]

Sometimes "health events" are identified by surveillance efforts, but more often they are brought to light by concerned residents.[2]

The Disease Cluster and Hotspot Map above depicts areas that have been investigated by government agencies and/or by private entities, which may include academicians, science-based organizations, or independent epidemiologists, as well as areas in which residents have raised concerns about unexpectedly high rates of disease. Areas represented by red dots are areas that are being or have been formally investigated by government agencies. Areas represented by yellow dots are areas that are being or have been investigated by private entities. Areas represented by blue dots are areas in which residents have raised concerns about unexpectedly high rates of disease in their communities, but those concerns have not yet been investigated.

Map Glossary of Terms

Disease Cluster – An unusual aggregation, real or perceived, of health events that are grouped together in time and space and that are reported to a health agency.[3] For the purposes of this map, an area which has been formally investigated by a public health agency.

Disease Hotspot – An area which is being or has been investigated by private entities, which may include academicians, science-based organizations, or independent epidemiologists, OR an area in which residents are raising concerns about unexpectedly high rates of disease.

Notes

[1] Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry. Agency for Toxic Substances and Disease Registry Glossary of Terms. Retrieved August 12, 2004 from http://www.atsdr.cdc.gov/glossary.html#G-A-

[2] Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report. (1990, July 27). Guidelines for Investigating Clusters of Health Events/ Retrieved August 12, 2004 from http://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm.

[3] Ibid. (Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report. (1990, July 27). Guidelines for Investigating Clusters of Health Events/ Retrieved August 12, 2004 from http://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm.)

HEALTH TRACKING & DISEASE CLUSTERS

The Lack of Data on Chronic Disease Incidence and its Impact on Cluster Investigations

Tony Dutzik
Jeremiah Baumann

U.S. PIRG Education Fund

SEPTEMBER 2002

Table of Contents

Index of Case Studies

Executive Summary

Each year, more than 1,000 calls are placed to public health officials regarding suspected local disease clusters. In many of these cases, investigators are called upon to determine whether rates of a disease in a particular community truly are excessive – and whether environmental exposures are to blame.

Requests for disease cluster investigations are just one sign of the broad public concern about the role environmental factors play in the development of chronic disease. Nearly 90 percent of Americans believe that environmental factors such as pollution cause disease or health problems.

Disease cluster investigations play an important role in responding to these concerns and protecting public health. Cluster investigations can help public health officials target resources for disease prevention and treatment, spur the discovery and cleanup of existing environmental hazards, and enable researchers to develop and test hypotheses about the possible links between environmental exposures and chronic disease.

Cluster investigations are notoriously difficult, even under the best of circumstances and with ample resources. However, in most states, the resources available for investigating disease clusters are extremely limited. In 1998, 26 states devoted less than one half-time person to cancer cluster investigations – a level of staffing virtually unchanged over the previous decade. States also demonstrate varying degrees of vigor in their response to cluster reports, with some states resolving as many as 99 percent of all cluster investigation inquiries during the course of the initial phone call.

To succeed in cluster investigations, researchers need complete, up-to-date information on the incidence of disease in a community; data that are typically collected in a disease registry or other health tracking system. To be effective, health tracking systems must be statewide, detailed, up-to-date, utilize multiple sources of information, and include active surveillance by public health officials to ensure that all cases of disease are recorded.

In many states, however, accurate tracking systems for chronic disease do not exist. Only three states – California, Iowa and Massachusetts – possess both cancer and birth defects registries that meet the highest standards for quality and also report having any system at all for the tracking of asthma. And almost no states conduct systematic tracking of learning disabilities, neurological disorders such as Alzheimer's and Parkinson's, metabolic diseases like diabetes, or auto-immune disorders such as lupus.

This report details the real-life costs of this knowledge gap as it relates to the investigation of 14 suspected disease clusters over the past decade. A review of completed cluster studies and other literature and interviews with state public health officials reveal that lack of access to high-quality health tracking data:

1) Causes long delays in cluster investigations;

2) Prevents public health officials from identifying disease trends;

3) Inhibits the identification of true disease clusters;

4) Reduces the number of cluster investigations carried out by states, meaning that some clusters go uninvestigated; and

5) Deters communities from getting the information and help they need when a suspected cluster arises.

While most states lag behind in their ability to track and investigate disease clusters, several states have shown the potential benefits of chronic disease tracking.

- Researchers using data from the California Birth Defects Monitoring System have shown that maternal exposure to air pollution and residence within a quarter-mile of a Superfund site are related to the development of certain birth defects.

- Texas public health officials used their ongoing surveillance of birth defects data to identify a cluster of neural tube defects in Laredo just months after it emerged. The state is now targeting public health assistance to the area.

- New York state officials are using a first-of-its-kind cancer mapping system to identify potential cancer clusters. The state is now investigating significantly elevated rates of breast cancer in seven Long Island zip codes.

With growing evidence that environmental factors play a significant role in the development of many chronic diseases – and with growing public concern over those links – the need to quickly and effectively identify and investigate disease clusters is greater than ever. The creation of a nationwide health tracking network would allow public health officials to conduct quicker, less resource-intensive, and more accurate investigations of disease clusters while providing researchers with the tools to better assess possible environmental links to chronic disease. Such a system would include:

- Tracking of cancers, birth defects, respiratory diseases such as asthma, neurological diseases such as Alzheimer's and other chronic diseases in every state.

- Tracking of environmental exposures, such as exposures to PCBs, heavy metals and pesticides.

- An early warning system to alert communities to immediate health crises such as heavy metal and pesticide poisonings.

- Federal, state and local rapid response capability to investigate clusters, outbreaks and emerging threats.

In addition to establishing a national health tracking network, public officials should encourage the linkage of health data with existing data on environmental conditions, promote public involvement

in cluster investigations, and take an aggressive stance toward both the prevention of new environmental hazards and the cleanup of existing hazards nationwide.

AMERICAN JOURNAL OF Preventive Medicine
A Journal of the American College of Preventive Medicine and Association for Prevention Teaching and Research

Cancer Map Patterns

Are They Random or Not?

Background

Maps depicting the geographic variation in cancer incidence, mortality or treatment can be useful tools for developing cancer control and prevention programs, as well as for generating etiologic hypotheses. An important question with every cancer map is whether the geographic pattern seen is due to random fluctuations, as by pure chance there are always some areas with more cases than expected, or whether the map reflects true underlying geographic variation in screening, treatment practices, or etiologic risk factors.

Methods

Nine different tests for spatial randomness are evaluated in very practical settings by applying them to cancer maps for different types of data at different scales of spatial resolution: breast, prostate, and thyroid cancer incidence; breast cancer treatment and prostate cancer stage in Connecticut; and nasopharynx and prostate cancer mortality in the U.S.

Results

Tango's MEET, Oden's Ipop, and the spatial scan statistic performed well across all the data sets. Besag-Newell's R, Cuzick-Edwards k-NN, and Turnbull's CEPP often perform well, but the results are highly dependent on the parameter chosen. Moran's I performs poorly for most data sets, whereas Swartz Entropy Test and Whittemore's Test perform well for some data sets but not for other.

Conclusions

When publishing cancer maps we recommend evaluating the spatial patterns observed using Tango's MEET, a global clustering test, and the spatial scan statistic, a cluster detection test.

http://www.ajpmonline.org/article/S0749-3797(05)00360-0/fulltext

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Assessing Health Problems in Communities

One of the most pressing questions everyone has had since the fight began is about health effects. Now after (enormous public pressure) a six-year fight, the state has agreed to ask the Agency for Toxic Substances and Disease Registry (ATSDR) to do a health study. Initially, (your group) you (was) were excited because (they) you thought that someone was finally going to provide some answers about health problems in (their) your community.

Then you heard rumors about the failures of ATSDR to meet the needs of local communities. Now you're confused and unsure what to do. Is ATSDR going to treat your community like they have every other community? History tells us they will.

Many people in your community are sick and have fought long and hard to get someone to evaluate their health problems. Because they want answers so desperately they may not want to turn ATSDR away. So, you decide to go along with the study. Now, it's not only important to know what to expect from ATSDR, but it's critical to have a plan on how to get the most from any health agency or institution who wants to investigate health problems in your community.

One important step is to define *as a community* what you want. Do you want a typical epidemiological study where a questionnaire is distributed throughout the community asking about health problems and the results are then compared to a matched unexposed community? Do you want a clinic set up in the community where people could be tested to evaluate their health? Maybe some portion of the community wants to be relocated or evacuated and you want ATSDR to recommend such action.

Once you're clear on the things you want, then you need to figure out how to achieve these goals. The investigating agency, whether it's ATSDR or someone else, is one of your targets. They are the ones who can give you valuable information and ammunition to help you get what you want. In most cases, they are only coming to your community because of the media, public attention, and pressure your group has already managed to put on the politicians and decision-makers. Be careful not to get totally distracted and let up on that pressure. It's vital to maintain this pressure, even while a study is being conducted in the community.

How can you tell if the investigating agency is friend or foe, or if the study will really help you achieve your goals? You need to ask three fundamental questions, the answers to which will give you a good sense of the intent of the investigators and the limits of the study:

- What are the goals of the investigation?
- How will the investigators get the information they need?
- How are they going to release the results?

Based on what you find out, you may decide that you don't want to participate in this study. Or you may decide you want to change the agency's plan to something that will be useful to your

group. Changing their plan will require a strong organized community effort and a plan to get your points across to the agency.

Involvement and Input at Every Step

The key to influencing the design of a health study is to have input at every step of the investigation, including:

- How the study is designed;
- How the study is actually carried out;
- The evaluation and interpretation of the results;
- The dissemination of the results; and
- Deciding what actions need to be taken as a result of the findings of the study.

The most critical of these steps is the first one. If the study is poorly designed, then nothing will come from the study. No amount of after-the-fact analysis can change a poorly designed study. You may need help to review the study design and protocols in order to understand if the study is properly designed, but groups often need money to hire medical or scientific experts to review the design of a health study. One demand you can make is for funds to hire your own experts. Anywhere from $10,000 to review a study design to $50,000 to participate in all the steps outlined above is reasonable.

Boycotting the Study

One way to change a study is to refuse to participate until you get what you want. By simply saying "no" to the study, you have a great deal of power. Unless the community participates, the agency has no study and will lose credibility if they fail to conduct a study because they didn't meet citizen demands for public participation.

Boycotting a study is not easy to pull off, (but it is doable). Just ask the Concerned Residents of the Yough (CRY) in Pennsylvania. After years of fighting a hazardous waste treatment and disposal facility, CRY finally convinced the Pennsylvania Department of Health to do a health study of the community. CRY asked for and received the study design. With the help of CHEJ, the community quickly found out that the study did not include specific questions about cancer, the number one concern in the community.

After much discussion and debate, CRY members agreed to boycott the study until it was changed to reflect their concerns. At first, the Health Department ignored these residents but found virtually no doors open to them as they went through the community. It wasn't long before the Health Department went back to CRY leadership with a new questionnaire that included the questions they wanted.

A Registry Versus a Study

An alternative to the traditional health study is to do a health registry. A health registry is conducted much like a health study. A questionnaire is developed and circulated throughout the community. The data is reviewed to determine the occurrence of health problems in the community and if any disease patterns exist. However, a control population is not needed.

Changes in health outcomes can then be tracked over time.

The biggest advantage of a registry is in the interpretation of the results. By looking at the rates of health problems in a community, you might find enough information to justify making demands for a clinic, a full scientific study, evacuation or whatever your goals are. At the same time, if you don't find much, you lose little, which contrasts with a full health study where if nothing's found, your community goes to the bottom of the list for action since you "proven" there's no problem in your community.

Before the Study Begins

If someone is going to do a health study in your community, here are guidelines you could use to help assure that the best possible study is conducted:

- The community must be given the opportunity to review the study design and protocols before the study begins (funds will likely be needed to hire someone with expertise to review this work);
- The study must address specific chemical exposures and adverse effects observed in the community;
- Avoid tests that generate results that cannot be interpreted;
- The study must have reasonable "power" to detect an effect if present (power is a statistical test that measures the “sensitivity” of a study to detect a certain outcome);
- Individual medical results must be reported to each individual before being released to the public (if applicable).

It’s also important to have good experienced scientists do the study. While in theory this is possible, it's often hard to achieve. Many communities where health studies are needed are high profile sites that quickly become politicized. Bureaucrats and politicians are under a lot of pressure at these sites to "do nothing," resulting in studies conducted by government agencies that are often inconclusive by design.

The best you can do is to make sure that the study design is critically reviewed, up-front, by experts working for the community, and that the study meets the criteria listed above. This approach should provide an honest assessment of what's going on in the community, even if ATSDR conducts the study. But don't be misled. No single study is likely to answer all of your questions, but a study design that benefits from community input and outside review is a good start. If you or your community would like to know more about how to influence the study design process or need help evaluating a study that has already been conducted, please contact CHEJ.

Written by Stephen Lester, Science Director
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Updated January 2010

Cancer Clusters

(An Article)

Cancer Clusters Among Children:
The Implications of McFarland

By: Penny Newman

Cancer clusters are one of the most frightening, frustrating situations a community can encounter. The families simply want to know what is killing their children and how to stop it from happening anymore, but these two questions are often answered last, if answered at all. I have yet to see any health agency define a "cause" for any of the clusters they have officially acknowledged. The lack of answers or assistance to the families of stricken children is a story filled with fear, helplessness, anger, self-blame, and disillusionment with the very people to whom they turn for help: their government officials.

One Small Town and Sixteen Children with Cancer

The McFarland story is a prime illustration of the dynamics involved when a "cancer cluster" is identified or suspected. It reads like a complicated murder mystery. The crime: at least 16 children stricken with cancer. The scene: a small rural community in Kern County, California. The suspects: everything from pesticides to electromagnetic radiation from radio transmission lines.

You have a multitude of witnesses, from frightened families to campaigning politicians, each with different accounts of what has happened and what needs to be down. You have the experts and investigators, all with their own pet theories but none with enough evidence to arrest the culprit and put a stop to the mindless killing. And, in the midst of all this confusion and panic, you have the families of the victims trying to make sense out of this senseless "crime" while the list of young victims continues to grow.

The scene of the crimes is the small rural town of McFarland located 20 miles north of Bakersfield. Like most towns in the San Joaquin Valley, McFarland has strong ties to farming, with a large proportion of the population of 6,500 made up of Hispanic families that earn their livelihood in the surrounding fields of cotton and citrus and almond orchards.

The crime is that at least 16 McFarland children have contracted cancer. The victims range in age from under two years to 15. The types of cancer include leukemias, retinoblastomas, Wilms (kidney) tumors, osteogenic (bone) sarcoma, a neroblastoma involving nerve tissue, and two different kinds of tumors of the muscle tissue. The latest tumor, detected in 1989, is a craniopharyngeononma, a brain tumor some argue is different and shouldn't be linked with the other cancers. Since 1983 six of the 16 children have died.

The first clues emerged in 1983 when Tresa Buentello, age 3, and Randy Rosales, 14, were diagnosed with cancer. Living on the same street, their parents began to wonder if the cancer cases, although different types, were connected. When a third child a block away was diagnosed with cancer, Randy's mother, Connie Rosales, realized something was terribly wrong and began to ask the Kern County officials

to evaluate whether high nitrates in the water or pesticide spraying in nearby fields could be the culprit. In July of 1984, Tresa Buentell died at the age of 4. The panic and realization of what was happening united the parents who began demanding that something be done.

Meet the Children of McFarland

The impact on the children of McFarland goes beyond the illnesses they suffer. This is dramatically and poignantly reflected in a letter received by Jacobo Durbin, a friend of Marta Salinas, a mother of three young girls in McFarland. He Writes:

"The facts and statistics offer only a very superficial glimpse of what is really happening in McFarland. There is the world of the children, in which their precious years of play and innocence are tainted with thoughts of cancer, death, and helplessness. One can only see this world by being with the children, a painful task at best, as the younger ones don't hesitate to say what they feel. Last summer I learned of a game that the children play called "My Baby has Cancer," in which a doll is diagnosed with cancer, meetings with the doctor end in the removal of limbs, until at last the doll dies. Then the children bury the doll in a shoe-box, mimicking the familiar lamentations of their parents. Words cannot express what it is like to hear a ten year old boy wondering aloud why all his friends are sick and dying. The most painful experience I have ever known was hearing Nadia, an 11 year old girl telling, through tears, of her suicide attempt. She had been suffering a migraine for days on end and one night she walked into the kitchen and slit her wrist open."

Prodding Reluctant Health Agencies

As is true of most instances of environmental poisoning, it wasn't the public agencies that identified the "cluster," but the local people who had to *convince* officials that this wasn't simply "random chance." By 1985, a total of eleven children had contracted nine different kinds of cancer between 1981 and 1984, a number four times the expected cancer rate. In addition, unusually high numbers of miscarriages, fetal deaths, and low-birth weight babies have been reported by doctors.

This combination of circumstances is so unusual that public officials finally declared McFarland to be the site of a childhood cancer cluster and ordered an extensive investigation in order to try to find what is causing such health problems.

Two-Phase Study

As difficult as it was to get the attention and acknowledgement of the agencies that a cluster existed, the struggle to find what is killing the children of McFarland has been overwhelming, confusing, and disappointing.

According to Dr. Rick Kreutzer, California Department of Health Services, Epidemiology Section and lead on the McFarland Task Force, the investigation has been divided into two phases. The first phase began in 1984 with a case control study conducted by Kern County. In this study families of the stricken children

were interviewed about their life styles and a control group of parents interviewed. A comparison was made to see if there are any specific factors that could account for the health differences. In this study a specific factor was identified: the parents of the stricken children were farm workers. Dr. Kreutzer indicates this distinction between stricken and non-stricken children was a mistake in data analysis and has since been refuted.

The second phase of the investigation is entailing environmental testing of air, soil, and water with prime suspects being metals in the soil, pesticide spraying, and solvents. Results so far have shown no soil levels of anything out of the ordinary and no air contaminants. Water testing has documented nitrates in water (a long standing problem in the area) and elevated levels of dibromochloropropane (DBCP) in one well. The well with DBCP was opened after the cancer cases appeared and has since been shut down; nitrate removal equipment has been installed. Nitrates are known to cause methemoglobinemia, a blood disorder commonly called the "blue baby syndrome." There is also some evidence that nitrates can form carcinogenic nitrosamines when ingested in "very high levels," resulting in stomach cancers in laboratory animals. While the reports say no pesticides were detected in McFarland's water, health experts point out that routine tests are capable of detecting only a handful of the 15,000 pesticides registered for use on state crops. Not finding any levels may simply mean that testing was not conducted for a particular pesticide, which in fact may be there. Moreover, most pesticide ingredients are lacking critical health data and full pesticide formulations are virtually untested.

Pesticides The Most Likely Killer

In a preliminary report released in February 1988, the Task Force concluded that the most promising lead in explaining the health problem in McFarland is the use of pesticides. The theory is that some environmental aberration occurred in McFarland during that three year period and the cancers are the result.

The fact that McFarland children have nine different kinds of cancers had left investigators baffled. Dr, Beverly Paigen, a geneticist and biochemist at Children's Hospital in Oakland, offered a possible explanation through a process called somatic recombination, a change in genetic arrangement that can be triggered by a toxic agent. Genetic research has shown that when a single gene has been altered, it is possible that different kinds of cancers may be caused by that mutation.

The task Force's search for possible contaminants is now focused on a dozen pesticides heavily used during a three year "window of exposure" period of 1980 to 1983. Since it is estimated that only 20 percent of pesticide use is reported, some wonder whether it is even possible to find "the" pesticide. Joyce Johnston of the Kern County Action Network notes, "The twelve pesticides identified by the task force as those most heavily used during that period are the ones reported. We have no idea what was heavily used and *not* reported."

What Do You Do When There Are No Answers?

From the very beginning, McFarland parents were cautioned that coming up with

answers would be difficult, if not impossible. The officials have lived up to that self-fulfilling prophecy. So with the uncertainty, unanswered questions, and continuing cancer cases appearing, the families are left to wonder, "Where do we go from here?"

The Community has been successful in forcing the Department of Health Services to conduct a screening program of the children of McFarland. The screening consists of a medical history, neuropsychological tests, physical measurements, and blood testing with samples "banked" for analysis in the future. Doctors are reviewing the findings and will be referring the children to specialists if any abnormalities are identified.

Lessons From Many McFarlands

McFarland illustrates the lessons learned at other communities like Love Canal, Times Beach, and Stringfellow Acid Pits (Southern California): you can't count on the agencies to "prove" there's anything wrong or whether it is linked to particular cause. Moreover, even if they "prove" a connection, that doesn't guarantee anything will be done to correct the situation. We've learned over and over again that the studies produce statistics to be analyzed away; that the tests produce numbers to be classified into safe levels or standards; and that experts can find ways to explain away anything.

It is only when communities stop trying to "prove" they deserve help, and begin *demanding* such help that they get results. By uniting with their neighbors and organizing specific actions, they may hope to meet some of their families' needs. Such demands may be bottled water or a new water system, assistance with meeting the financial burden of medical costs, full disclosure of pesticides used in the area, continued health monitoring, or relocation to a less hazardous area.

McFarland is only one of many "clusters" in the San Joaquin Valley and across the nation. There are other communities facing the same nightmare: California towns like Fowler and Rosamond; Maryvale, Arizona; and Margan City, Louisiana. There are undoubtedly hundreds more that have yet to be identified. McFarland may be an early warning of nightmares to come.

Six Steps to Action

History shows us that the only effective way to resolve a toxic problem is for citizens to join together. By doing so, they create enough pressure on government and corporations to insure that the needs and concerns of people are addressed.

- **Research**. Observing what is going on around you and talking to your neighbors is the first research step in forming a group. You want to gather enough information to know that your problem is real and to have enough detailed information to recruit people. Network with other communities that are facing similar problems. This will cut down on the amount of time you have to spend gathering information and will help you avoid mistakes others have made. These contacts are available through CCAEJ as well as other organizations.

- **Community Analysis**. Once you have some basic information and are convinced there is a problem, you need people. Identify the self interest of the people you're trying to recruit: (e.g., are their families and/or property values affected?)
  Look at your community. Mapping it helps identify possible allies (known leaders in the community); resources (churches, schools); potential adversaries (Chamber of Commerce).
  With suspected health problems, develop a "measle map." Identify each house on a map where the illnesses are and use colored stick pins or ink pens to mark them. This show graphically where the problems are so everyone can see them, and many times leads to identifying possible links to a source of contamination. This is not a health study but simply a way to let others see where the problem is.
- **Recruitment of others**. Develop a fact sheet (keep it simple). Get a name for your group with which people can identify.
  There are two ways to recruit: 1) Go door-to-door, talking to people one-by-one; and 2) inform the public at large.
  The hardest thing for most people and yet the most effective way to get people involved is to knock on doors and talk to people. It really is less painful than most people think. Use your fact sheet and a petition (petitions don't really get you anything except names, addresses, and phone numbers of people who are concerned and will support you so you can contact them later).
  Utilize the media. Hold community meetings that are well planned, informative, and accomplish something. People will come back and get involved if they know you are doing something toward solving the problem.
- **Goals and Action Plans**. Define goals and outline a plan of action using a step-by step approach. Develop a platform. Do this by putting the following items on a chalkboard or newsprint:

  What do we want?
  1.

  2.

  3.

  Who can give it to us?

  1.

  2.

  3.

  How can we make them do it?

  1.

  2.

3.

Develop a plan of action or campaign to obtain what you demand. It needs to be a step-by-step, well thought out plan. The plan will not be done on a day-by-day basis, but will build in momentum targeted on the right person until the pressure reaches the point they'll do anything you ask to get you off their backs.

- **Words of Caution**. Beware of distractions. You can easily get into arguing with the agencies over whether you should test three inches down in the soil or four feet. These side trips can divert you from the goals you want to achieve.
  Notoriety is a mixed blessing. It gives you needed coverage, but also attracts politicians running for office and national groups wanting you as their "poster child". Use the media as part of your strategy but don't let the number of articles in the paper become *the* strategy.

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AGRARIAN ADVOCATE

FREE

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FALL, 1988

Agrarian Advocate Interview with Beverly Paigen, MD

CANCER CLUSTERS -- SEARCHING FOR CAUSES

The San Joaquin Valley town of McFarland, population 6,000, is 26 miles north of Bakersfield. During the past 13 years, 15 youngsters there have developed nine different types of cancer. This is at least four times the normal rate. Nine of the children have died. There are several other cancer clusters in the San Joaquin Valley. Rosamond is one of them.

Dave Watson, Interviewer

Dr. Beverly Paigen is a Senior Research Biochemist at the Children's Hospital Oakland Research Institute. She has investigated the affects of toxic wastes on children in a number of American communities including such infamous toxic waste sites as Love Canal (Niagra Falls, NY); Stringfellow, California; Woburn, Massachusetts; Times Beach, Missouri; and most recently, McFarland, California. Dr. Paigen is now a nationally recognized expert on community exposure to low-level toxic pollutants and is on the forefront of research in this controversial specialty. She is also the co-founder of Citizen's Clearinghouse for Hazardous Wastes based in Arington, Virginia.

Dr. Paigen was interviewed for The Agrarian Advocate by Dave Watson, a toxcologist doing research at the University of California, Davis.

DW: How did you get involved in research into communities affected by toxics problems?

BP: When I first came to Children's Hospital seven years ago I had a two-pronged research program: the effects of toxins on children's health and the genetics of heart disease. The research on children has died down, while the other area has progressed very rapidly. Part of this is the political climate and the availability of funding.

I'm not doing anything real active right now, except that I do serve as advisor or consultant to communities that have had exposure to toxics. I've had a lot of field experience reviewing data and visiting sites, but my research into the effects of toxins was one particular study on about a thousand kids living near Love Canal, some in the contaminated area, and some in a nearby community.

I looked in particular at birth defects and low birth-weight babies, which were both elevated. I was particularly interested in hard objective data rather than symptoms that are subject to recall bias. I also focused on height. I figure that if toxins are entering into the system either prenatally or during growth, that that will affect the growth rate. Many different toxic chemicals will affect the growth rate. It's a common underlying toxic effect

We found that birth weight was reduced, and that it was reduced primarily because of retarded growth, not because the babies were being born too early. We also found that children living in Love Canal were shorter than children living elsewhere, and that girls' menstrual periods were delayed as would be expected if their growth were retarded.

We also found a lot of other health problems at Love Canal -- skin rashes, constant irritation of the eyes, urinary incompetence, seizures and learning problems.

DW: Were you able to determine which chemicals were responsible?

BP: This was one of those horrible sites where you had 250 chemicals, for which the toxicicity of 100 wasn't known because they are breakdown products. We used surrogate measures like distance of the house from the canal and length of time that the child had been living there to show a dose response effect.

DW: Why do you focus on children?

BP: They are so much more susceptible to toxic chemicals. Their nervous and immunological systems are immature. They don't have all of the complications that adults have like smoking, drinking and additional exposures. They're easier to examine, they also have a higher rate of metabolism – they eat more, breath more and drink more.

DW: In what other communities did you work?

BP: The other place that I was heavily involved was Woburn Massachusetts where there is trichloroethylene in the water and a cluster of childhood leukemias. Some people from the Harvard School of Public Health did studies on the children in that area and found the same kinds of things that I had at Love Canal – increase in seizures and other

continued on page 6

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Paigen continued:

neurological problems, increase in birth defects and something that I didn't show, increases in neonatal death.

McFarland and Rosamond are the only sites where an increase in childhood cancers is carefully documented. In other cases, the populations are too small. It's only when you have the really horrible cases such as a water supply or something which is affecting an entire community, that you can see those kinds of affects. In many sites there are only 20 or 100 homes. In Woburn, there were thousands of homes. In McFarland, there is a whole town of about six thousand people.

You know, epidemiological data didn't turn up the cancer clusters. People turned up the cancer clusters. In all of the sites where I have worked, it was the people who said "we have a health problem here." And then the scientists have come in and done their thing and confirmed it. So my advice is that people need to band together. There's strength in unity.

DW: What are the patterns in McFarland?

BP: Rates of fetal deaths, infant deaths and low-birth weight babies are all elevated and they were elevated at the same time as the childhood cancers. I said to the State that it had to be a chemical because you wouldn't by chance have all four of these things happening simultaneously. Some of the deaths were caused by birth defects -- two babies were born without a brain.

Now the interesting thing to me was that the fetal deaths and infant deaths started a year before the childhood cancers and they were high for three years and then they went back down and a year later the childhood cancers went up and they stayed up, but for a little longer. They too have started to come back down, but they still aren't back to normal levels. This is what you would expect with a cancer-causing agent.

The kinds of cancer are pretty interesting too. The most common kind of childhood cancer is leukemia, but leukemia is conspicuously missing from this cluster. Initially, there were two leukemia cases, but those two cases were diagnosed in 1978, while all the other cancers started in 1981. Those may have been background levels. What we see are brain tumors, eye tumors, bone tumors, and kidney tumors.

One thing that I thought was encouraging when I looked at this was that the infant deaths did drop back down to normal, so it was like a three year pulse. I looked at the infant and fetal deaths and looked at how thay were distributed throughout the year, and I found that they were not evenly distributed. They were very high in the months when there is a lot of spraying -- April, May and August. This may be a clue.

DW: Do they know what could be causing the cancer cluster?

BP: For a while I thought that it might be the nitrates in the water which have been there for a long time. Now I think the nitrates might have caused some ill effects, but I just don't think they would have caused the cancers.

The State looked a lot at the lifestyles of the families -- occupation of the parents, the kind of water they drank when they were babies, all kinds of things. There was nothing in there.

Then we went and looked at the homes. They tested for pesticides in the soil and around the homes. Some people have said that they didn't sample right and that could be. But it didn't really look like those homes did have anything in them.

It really looked very much as if it might be the aerial spraying. That would have enormous implications for the state of California and indeed the whole nation. They took the pesticide use permits from the California Department of Food and Agriculture. Some people question the legitimacy of these permits and say that you can't rely on the data at all, but I feel that it is better than nothing. So they analyzed the data to see if there was anything that was increased in the right years. There were four chemicals that looked pretty interesting. One called Dinoseb had all the relevant toxic effects and it was used very heavily in the right years - '81, '82 and '83.

Another strong possibility is that the area of town is a low area and there was a lot of dumping of farm wastes like old seeds treated with fungicides and by-products of sugar-cane processing. Because it was a low spot there would have been a collection of drainage there. And there was a lot of construction of new homes at about the right time.

So there are two possibilities and we don't know which is true yet. I think what they need to do is to look at some other farm communities where similar pesticides have been sprayed and see if there is an increase in the kinds of cancer clusters. We know about this one because the people complained, but there could be others and we don't know yet because nobody's looked carefully for them.

DW: How were these studies funded?

BP: The Love Canal study was hard to get funded because it was controversial, but the Environmental Defense Fund rasied money for it by going to foundations that support environmental and social issues.

DW: How would you recommend that people proceed who are living in communities in agricultural settings where they know that aerial sprays are occurring? Given the lessons of McFarland and given this hypothesis that aerial spraying may be epidemiologically linked to cancer clusters.

BP: You know, epidemiological data didn't turn up the cancer clusters. People turned up the cancer clusters. In all of the sites where I have worked, it was the people who said "we have a health problem here." And then the scientists have come in and done their thing and confirmed it. But I don't think that there was a single one where the scientists went out and found it. So my advice is that people need to band together. There's strength in unity. And they have to do something about it.

The thing that amazes me when I talk to people in McFarland is that when they're sprayed they get sick. When the spraying happens they all have sore throats, they all have burny eyes. Many of them have skin rashes. Even if there wasn't a cancer cluster, I don't think that people should have to live like that and I feel that whether or not there's a cancer cluster, people should band together and protest.

The State Health Department is in a responsive mode. They don't go out and seek problems. They respond to problems. So you need to be organized, you need to have a spokesperson, you need to make the press. That's how things get done. That's what I feel now. If the people can gather together and document the problem -- that's very very tough. But sometimes they can. And sometimes they can't.

The people at Love Canal just kept a log and they had feelers out in the community. People

continued on page ;

Paigen continued:
called in when they had sore throats or colds or this or that and it was all collated so that they could search for patterns. I think that this is the kind of thing that has to happen.

There's nothing so horrible as a child with cancer. But I do think that it is not the only health problem that we should be focusing on. It requires such a lot of time. I think that problems like low birth weight babies and miscarriages and fetal death show up at much smaller populations and that they're sort of a great indicator that worse things could happen. So I think that those are very important. Even skin rashes. You know, you get skin rashes for other reasons, but in most communities of active chemical exposure, whether it's in the water or the air or the soil, you have skin rashes.

DW: It's time to get away from this dead body sort of stuff.

BP: Yes. I think we should be focusing on the early warning signs. There are also some very simple neurological tests that can be done with portable machines. Many of these chemicals are neurotoxins. Neurotoxicity is probably a more serious condition than cancer clusters. First, because the peripheral nervous system is critical. You know, it leads to numbness, stumbling, headaches, tingling and dropping things. And if you think about children, this is why they had epileptic seizures and learning problems at Love Canal. The central nervous system was being attacked. And I can't think of anything worse than having reduced function of the nervous system when you're a child and having to learn speech and how to go to school and read and write and so on.

People tend to focus on the acute health effects. I saw a site where everybody wore glasses because it was affecting their optic nerves. I worked at another place where the water was contaminated and people took a shower and after the shower they were dizzy, light-headed, and fainting because the chemicals were evaporating from the water. And they would have skin rashes from the shower. So I think these other things are not being looked at. I don't think we should wait for cancer clusters. Of all the sites I've worked with, there's only been two of the eighteen or so that really had the marks of a cancer cluster. There are other symptoms.

So I think that the only answer is when people try to solve it by themselves. What grew out of Love Canal was an organization called Citizen's Clearinghouse for Hazardous Waste, that I helped to found. CCHW helps communities with these problems by putting them in touch with people of expertise. CCHW is trying to help people get the tools. They bring a lot of information. Like how to get your community organized. How to hire yourself a lawyer and make him work for you. So you want to do a health study, think before you count. Who are the experts? These are the kinds of things. They have people organized.

There are dozens of people, dozens of grassroots efforts in the United States now. I think that people have to decide that you don't wait for a cancer cluster. If you get sore throats every time your neighbor's farm sprays, do something. ▼

Rachel's Environment & Health Weekly #559

Providing news and resources for environmental justice – August 14, 1997

CHILDHOOD CANCER AND POLLUTION

A new peer-reviewed study in England shows that children have an increased danger of getting cancer if they live within three to five kilometers (2 to 3 miles) of certain kinds of industrial facilities.[1] The study, by E.G. Knox and E.A. Gilman, finds that the danger is greatest within a few hundred yards of pollution sources and tapers off with distance. The incidence of childhood cancers per 100,000 children in England and the U.S. has been rising steadily for at least 20 years.

The new study examined data for 22,458 children who died of leukemia (cancer of the blood-forming cells) or of solid cancers during the years 1953 to 1980 in England. The study looked at home address at time of birth and home address at time of death, then measured the physical distance from these addresses to nearby industrial facilities.

Excesses of leukemias and solid cancers among children were found near the following kinds of industries:

• oil refineries, major oil storage installations, railside oil distribution terminals, and factories making bitumen (a British term for asphalt, crude petroleum and tar).

• automobile factories, auto body construction factories, and auto body repair shops;

• major users of petroleum products including paint sprayers, fiber glass fabricators, paint and varnish makers, manufacturers of solvents, plastics and detergents, and galvanizers (zinc metal platers).

• users of kilns and furnaces, including steel mills, power plants, cement manufacturers, brick makers, crematoria, and foundries for iron and steel, aluminum, and zinc.

• airfields, railways, highways, and harbors.

This study was also interesting for what it did *not* find:

• Rubber manufacturers showed slight increases in childhood cancers nearby, but tire manufacturing plants did not. Likewise, brake manufacturing showed no excessive childhood cancers nearby.

• Despite the use of solvent-based cleaning, electroplating plants showed no childhood cancer increases nearby.

• Twenty-two factories making halogenated hydrocarbons (chlorinated and fluorinated) had no apparent effect but 32 other solvent manufacturers showed cancer effects up to 5 kilometers (3 miles) away.

• Metal casting (aluminum and zinc), metal forming, and welding probably account for the effects seen near automobile manufacturing plants, the authors say. However, casting and refining of lead showed no childhood cancer effects. The manufacture of automobile batteries, on the other hand, exhibited strong effects. The authors speculate that it may be the manufacture of battery casings (plastics forming, and use of solvents) that create the childhood cancer effect, rather than the lead itself.

• Other industries that did not seem to be associated with childhood cancers included agricultural fertilizer rail terminals; TV transmitters; cake and biscuit bakers; dry cell battery manufacturers; magnetic tape makers; nuclear power plants; PVC manufacturers; and the makers of wood preservatives.

• Benzene manufacturing plants were not associated with nearby clusters of childhood cancers. The known leukemia hazard from benzene may have led to special containment measures.

The findings for leukemias and for solid cancers were the same.

Among children who had changed addresses between birth and death, the cancer hazard could only be seen near the birth address, implying that exposure to pollutants shortly before or after birth caused the cancers.

Knox and Gilman, the authors of this study, have spent several years developing analytic techniques for identifying small-scale cancer clusters, usually cancers occurring within 150 to 300 meters (roughly 150 to 300 yards) of each other.[2] The authors say they are sure their techniques can now identify cancer clusters at the neighborhood level. "First, our recent analyses have effectively dispelled caveats about the reality of short range case clustering and the existence of geographically localised hazards is not now in doubt. Proximity studies are no longer concerned with this issue and can be directed solely at asking what those hazards might be," they say.[1]

This latest study takes these techniques the next step and links the cancer clusters to nearby sources of pollution, particularly those involving large quantities of petroleum.

The weakness of this latest study, the authors say, is that it cannot rule out the possibility that there are excessively large numbers of children living near industrialized facilities, which could create the false impression of high cancer rates. The authors examine this question as best they can, and they show that, in general, there are few residences within short distances (a few hundred yards) of major factories because associated facilities (roads, parking lots, garages, etc.) compete for space with residential buildings.

The authors conclude that childhood cancers cluster around two general kinds of facilities:

• producers, refiners, distributors, and industrial users of petroleum fuels and volatile petroleum products; and

• manufacturing processes using high temperature furnaces, kilns, and combustion chambers.

Some operations, notably internal combustion engines and oil fired furnaces, meet both criteria.

The authors of the study say there may be three mechanisms by which childhood cancers are caused:

• Gases and volatile organic compounds reaching the children or their pregnant mothers directly;

• Parents' germ cells being harmed during occupational exposures, giving rise to children who are predisposed to cancers;

• Occupational contamination carried home on clothing, skin, or breath.

Of the three mechanisms, the authors say they believe direct exposure of children or their pregnant mothers is the most likely.

The authors say their study may have missed many local sources of petroleum exposure of children, such as domestic and commercial heating systems, oil storage bunkers, oil delivery spills, small machine shops, bus stations, school or hospital chimneys, municipal incinerators, gasoline stations, etc.

Childhood cancers could be caused by at least 3 mechanisms:

- Pollutants damaging the inherited genetic material (DNA) in cells;
- Pollutants damaging the immune system which would otherwise prevent cancer cells from surviving;
- Pollutants damaging mechanisms of cell division. (Cancer is uncontrolled cell division.)

These latest findings, that childhood cancers are clustered near industrial facilities, contradict the official view of childhood cancer, at least in the U.S. The National Cancer Institute (NCI) wrote in 1993, "Time trends in childhood cancer are not likely to be affected by environmental agents because very few are known that cause cancer within the pediatric age-span, and exposures have been rare or limited." And: "Clusters of childhood cancer occur very often by chance and almost never because of environmental agents."[3] Nevertheless, the NCI does say that children exposed to radiation (as at Hiroshima and Nagasaki) can develop cancers. Exposure to benzene could cause childhood leukemia, says NCI, because benzene affects chromosomes the same way radiation does. The children of mothers treated with diethylstilbestrol (DES) -- a drug given to women in the 1950s to prevent miscarriage -- can develop childhood cancers, NCI acknowledges.

NCI reports that the incidence (per 100,000 children) of many childhood cancers have increased steadily during the period 1973-1990. All childhood cancers combined have increased at the rate of 0.9% per year (0.9% per year among whites, and 1.0% per year among African-Americans). Cancer of the brain and central nervous system have increased at 1.8% per year. Leukemias have increased at 1.8% per year. Non-Hodgkin's lymphomas have increased at 1.4% per year. Kidney cancer has increased at 1% per year. However, thanks to surgery, radiation treatments, and chemotherapy, death rates for all these childhood cancers have declined steadily since 1973 at an average rate of 2.9% per year even as the incidence rates have increased.[3]

U.S. environmental officials discourage the kind of study reported here. Each year U.S. Environmental Protection Agency (EPA) collects data on toxic releases as self-reported by industrial polluters, thus creating the annual Toxics Release Inventory, or TRI database, which is authorized by federal law. However, EPA has never assigned any staff to check the quality of the self-reported data, thus making any studies based on the TRI data suspect. Furthermore, when John R. Stockwell, a physician employed by the U.S. Environmental Protection Agency (EPA), developed a technique for linking data from the TRI database with disease rates near pollution sources in Chattanooga, Tennessee, EPA officials immediately tried to fire Stockwell. (See *REHW #366, #392.*) Because of citizen protests, Stockwell managed to keep his job, but he has not undertaken any similar studies since then, and neither has anyone else within EPA. EPA chief Carol Browner has issued a memo specifically ordering EPA staff to "stay away from linking human health effects and the TRI data." (*REHW #392*)

Another EPA official who tried to link industrial toxic releases to human health has also found himself in serious trouble. Brian Holtzclaw, an environmental engineer employed by EPA but "on loan" to the state of Kentucky, urged the study of massive toxic releases from an Ashland Oil refinery to see if they correlated with disease rates in neighboring communities. He tried to bring in John Stockwell to study Ashland's toxic discharges, and he himself released some pollution data to local citizens. Holtzclaw was immediately terminated from his Kentucky projects and reassigned to Atlanta, Georgia. Holtzclaw fought the reassignment. Hundreds of environmental groups and individuals all across the country have signed letters and petitions on Holtzclaw's behalf. After a legal battle, EPA -- without admitting any wrongdoing -- settled with Holtzclaw for $20,000 and a written promise that he could continue to work on environmental justice issues. However, Holtzclaw's court battle against the U.S. Department of Labor and the state of Kentucky continues. He wants his job back in Kentucky and he wants his court costs reimbursed.

The Stockwell and Holtzclaw cases send an unmistakable message from EPA chief Carol Browner to all EPA employees: Beware. The relationship of pollution to human disease is a forbidden topic of study.

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[1] E.G. Knox and E.A. Gilman, "Hazard proximities of childhood cancers in Great Britain from 1953-80," *Journal of Epidemiology and Community Health* Vol. 51 (1997), pgs. 151-159.
[2] See E.G. Knox, "Spatial clustering of childhood cancers in Great Britain," *Journal of Epidemiology and Community Health* Vol. 50, No. 3 (June 1996), pgs. 313-319. And: E.G. Knox, "Leukaemia clusters in childhood: geographical analysis in Britain," *Journal of Epidemiology and Community Health* Vol. 48, No. 4 (August 1994), pgs. 369-376. And: E.G. Knox, "Leukaemia clusters in Great Britain. 1. Space-Time interactions," *Journal of Epidemiology and Community Health* Vol. 46, No. 6 (December 1992), pgs. 566-572. And: E.G. Knox, "Leukaemia clusters in Great Britain. 2. Geographical concentrations," *Journal of Epidemiology and Community Health* Vol. 46, No. 6 (December 1992), pgs. 573-576. And: E.A. Gilman, "Childhood Cancers: space-time distribution in Britain," *Journal of Epidemiology and Community Health* Vol. 49, No. 2 (April 1995), pgs. 158-163.
[3] Barry A. Miller, and others, editors, *SEER CANCER STATISTICS REVIEW 1973-1990* [NIH Publication No. 93-2789] (Bethesda, Maryland, 1993), pgs. XXVII.1 to XXVII.15.
[4] Scott Learn, "Project director says EPA won't let doctor participate," *Lexington [Kentucky] Herald-Leader* March 20, 1994, pg. A15. And see: Andrew Melnykovych, "EPA to Pay $20,000 settlement to employee," *The [Louisville, Kentucky] Courier Journal* November 3, 1995, pg. 1. And see: Southern Organizing Committee for Economic and Social Justice (SOC), "Hundreds of Citizen Groups Call on Department of Labor to Uphold Rights of Environmental Whistleblower," press release dated October 11, 1996; for further information, contact SOC at (502) 776-7874, or (404) 755-2855, or Mr. Holtzclaw himself at (404) 562-8868.

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EPA may replace CDC as cancer cluster surveillance agency

The U.S. Environmental Protection Agency (EPA) would replace the Centers for Disease Control and Prevention (CDC) as the federal government's lead agency for investigating suspected residential clusters of cancer, birth defects and chronic diseases, under the newly-proposed "Strengthening Protection For Children and Communities From Disease Clusters Act" under consideration in the U.S. Senate.

"The real strength (of the new bill) is it brings the EPA to the table when there's concern about some health effect," National Disease Clusters Alliance (NDCA) director Terry Nordbrock said.

That came as welcome news for some familiar with the CDC's troubled investigations of two recent childhood leukemia clusters.

The CDC is a world-renowned center of expertise on infectious diseases. But cancer epidemiologists and toxicologists contacted by epiNewswire expressed skepticism that the CDC or the CDC's Agency for Toxic Substances and Disease Registry (ATSDR) competently and aggressively investigate the environmental correlates of chronic disease clusters.

At recent congressional hearings, ATSDR Director Henry Falk was asked about the epidemiology of cancer clusters with suspected environmental causes. He described only the scientific limitations of such studies, according to news reports.

CDC failed to tell public of errors in Fallon leukemia cluster study

Much of the skepticism about the CDC's commitment to cancer cluster investigations is rooted in the agency's mishandling of an investigation into the Fallon, Nevada childhood leukemia cluster.

The Fallon cluster was the most profound elevation in childhood leukemia rates ever recorded. Between 1999 and 2005, at least 15 children in the small rural town of 8,500 were diagnosed with acute leukemias. Another boy was diagnosed in 1997. In addition, another six older children were diagnosed during the early years of the cluster with idiopathic thrombocytopenia, a local health care provider told epiNewswire.

The CDC and ATSDR investigated the Fallon cluster and a simultaneous childhood leukemia cluster in Sierra Vista, Arizona, between 2002 and 2007. An EPA scientist complained at the time that the CDC was "guarding its turf" in the Fallon cluster investigation, refusing to involve environmental epidemiologists or toxicologists from other agencies.

CDC contractor Battelle's analysis of toxic chemical body burden (blood and urine concentration) data included systematic errors involving the use of incorrect denominators, a CDC official acknowledged to epiNewswire.

Battelle had been paid several million dollars by the U.S. Navy to help assess and clean up toxic waste at the Fallon Naval Air Station just south of town. CDC officials were unaware of that potential conflict of interest when they contracted Battelle to study the possible role of some of those toxic chemicals in Fallon's leukemia cluster, an agency administrator told epiNewswire.

The CDC never publicly acknowledged the data analysis errors in the Fallon study or Battelle's potential conflict of interest in that study. In fact, the CDC based some of its conclusions on the Battelle analysis, without disclosing in its final report on Fallon that there were doubts about the validity of that analysis.

The CDC's discovery of the Fallon leukemia data analysis errors came just months after the agency's public embarrassment over its own erroneous claims about adult obesity-related mortality rates, noted a former CDC employee familiar with the obesity study.

The CDC emphasized a correlation it identified with a particular gene, *SUOX*628A*, which was present in most of the leukemia case children in the Fallon and Sierra Vista clusters, but not healthy control children from each community.

But when statistical corrections were made for the large number of genes tested in the study, the SUOX finding was statistically non-significant, CDC officials acknowledged.

"This allele is about as common as blue eyes", University of California San Francisco genetic epidemiologist and leading childhood leukemia researcher Joseph Wiemels said of the CDC's finding. "It is certainly not the cause of the cluster."

Senate Bill 3681 was introduced by Senate Environment & Public Works committee chairwoman Barbara Boxer (D-CA), Sen. Amy Klobuchar (D-MN), Frank Lautenberg (D-NJ), and Bill Nelson (D-FL). The bill is known as "Trevor's Law," named for Trevor Schaefer, 20, a childhood brain cancer survivor.

The bill would authorize the EPA to investigate environmental pollution's role in disease clusters, and was drafted in the wake of studies of a rare male breast cancer cluster among Marines once stationed at Camp LeJeune, North Carolina, a brain cancer cluster in Acreage, Florida, and a cluster of birth defects in Kettlemen City, Calif.

"Whenever there is an unusual increase in disease within in a community, those families deserve to know that the federal government's top scientists and experts are accessible and available to help, especially when the health and safety of children are at risk," said Sen. Boxer.

As epiNewswire reported in 2007, most state health departments lack the resources and staff expertise to investigate suspected chronic disease and birth defects clusters.

Bryant Furlow reported on the Fallon leukemia cluster and the CDC's study for New Scientist magazine and The Lancet Oncology. Furlow is an award-winning investigative medical journalist.

Environmental News: Media Center

Press Release

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FOR IMMEDIATE RELEASE

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Disease Clusters: Federal Help Needed To Confirm Existence, Determine Sources
Report Documents Clusters in 13 states to Highlight Need For Chemical Policy Reform

WASHINGTON (March 29, 2011) – Confirming disease clusters and finding their causes are extremely difficult, but better federal coordination and federal assistance for state and local officials and citizens could help do both, according to Dr. Gina Solomon, NRDC senior scientist who testified before the Senate Environment and Public Works Committee today.

Drawing from research by federal, state, or local officials and peer-reviewed studies from academics, the Natural Resources Defense Council and the National Disease Clusters Alliance have identified 42 disease clusters in 13 states in an issue paper submitted to the committee today.

In the study, state-by-state fact sheets cover confirmed clusters of numerous types of cancer, birth defects, and other chronic illnesses as well as several currently under investigation by federal, state or local health agencies. The groups looked at clusters that have occurred since 1976 when Congress passed the Toxic Substance Control Act, or TSCA, legislation designed to regulate the use of toxic chemicals in industrial, commercial and consumer products.

“Communities all around the country struggle with unexplained epidemics of cancers, birth defects, and neurological diseases,” said Solomon, co-author of the issue paper. “The faster we can identify such clusters, and the sooner we can figure out the causes, the better we can protect residents living in the affected communities.”

Solomon testified at an oversight hearing on “Disease Clusters and Environmental Health.” Other witnesses included Erin Brockovich, who became a household name when her fight to document a disease cluster in the tiny town of Hinkley, California was turned into a major motion picture, and Trevor Schaefer, a 21-year old survivor of brain cancer from Boise, Idaho. Schaefer and his family have created a foundation that has been fighting for better investigations into the causes of cancer clusters.

Solomon discussed the paper: “Health Alert: Disease Clusters Spotlight the Need to Protect People from Toxic Chemicals.” This is the first installment of a plan to review all 50 states. In the first study, NRDC and NDCA looked at clusters in **Texas, California, Michigan, North Carolina, Pennsylvania, Florida, Ohio, Delaware, Louisiana, Montana, Tennessee, Missouri** and **Arkansas**.

In only one of the 42 clusters -- in Libby, Montana-- was a specific source of chemical contamination identified: asbestos. In many communities, such as Camp Lejeune, North Carolina, the case grows stronger that documented exposure to toxics has harmed the health of community residents.

"Communities deserve to have confidence that disease clusters will be found and that their concerns will be adequately addressed," said Terry Nordbrock, executive director of the National Disease Clusters Alliance and co-author of the issue paper. "And given the bipartisan support for the proposed 'Trevor's Law' to reform the way we respond to disease clusters, communities have a new reason to hope."

Investigations into environmental causes of disease clusters are complex, expensive, and often inconclusive, partly due to limitations of scientific tools for investigating cause-and-effect in small populations.

The groups support legislation introduced by Sens. Barbara Boxer, D-Calif. and Michael Crapo, R-Idaho, that would improve federal coordination of efforts to assist state and local officials, and respond to citizen concerns about disease clusters in their communities. These groups also want to see legislation to reform TSCA enacted to help stop these clusters from forming in the first place through exposure to unregulated and untested chemicals.

"The documented disease clusters may just be the tip of the iceberg, and they illustrate the need for the federal government to work with state and local governments, and those living close to these clusters, to figure out what is making people sick," Solomon said. "In addition to helping communities already facing a disease cluster, the country's overall chemical policies need to be changed to prevent the creation of additional disease clusters: requiring chemical manufacturers to ensure the safety of their products and reducing or eliminating toxic releases into air, water, soil and food through stronger environmental controls and tough enforcement of those requirements."

The full issue paper can be found at www.nrdc.org/health/diseaseclusters

Report, Hearing Focus on Disease Clusters

By Emily P. Walker, Washington Correspondent, MedPage Today
Published: March 29, 2011

WASHINGTON -- A new report highlights 42 locations throughout the U.S. that have alarmingly higher incidences of certain diseases, including cancer and birth defects.

The report, released by the Natural Resources Defense Council (NRDC) and the National Disease Clusters Alliance, surveyed 13 states in which so-called "disease clusters" had been identified by media reports and by local and state health agencies.

In most cases, the diseases were suspected to be caused by environmental factors, Gina Solomon, MD, MPH, senior scientist at the NRDC and one of the authors of the report, said in testimony before the Senate Committee on Environment and Public Works, which held a hearing Tuesday on the issue of disease clusters.

One particularly bizarre cluster is occurring in Camp Lejeune, N.C., where 64 male Marines living on the base have been diagnosed with breast cancer. Contaminated drinking water at Camp Lejeune is thought to be a possible carcinogen, said Solomon.

Other clusters include:

- Leukemia in Fallon, Nev., where from 1999 to 2001, 11 children were diagnosed with leukemia. Scientists calculated that a cluster of this magnitude would occur naturally, by chance, once every 22,000 years
- Testicular cancer in Prairie Grove, Ark., a town of 2,500 people, including three cases in 14-year-old boys
- Birth defects in Kettleman City, Calif., a town of 1,500 people, including 20 babies born over less than two years with birth defects
- Lou Gehrig's disease in Herculaneum, Mo.
- Polycythemia vera, a rare blood disorder, with four cases occurring in people living on one road in eastern Pennsylvania

"Although it is difficult to conclusively prove what caused any specific disease cluster, we can gather invaluable clues and hints from these tragic events," Solomon told the Senate committee.

Some clusters of cancer, birth defects, and other chronic illnesses such as asthma are thought to be linked to chemical exposure or other toxic pollutants. A 2010 report from the President's Cancer Panel pointed to pesticides, fertilizers, pharmaceutical by-products that enter the water supply, household chemicals, and tanning beds as potential causes of disease. Emissions from cars, trucks, and planes add to the toxic mix, the authors wrote. They concluded that "the true burden of environmentally induced cancer has been grossly underestimated."

In an interview with *MedPage Today,* Solomon said she was surprised to learn that the CDC does not track or investigate disease clusters. In the 1990s, there was an investigation into a a childhood leukemia cluster in Woburn, Mass. that was discovered by mothers who were sitting with their children in the waiting room at the Dana Farber Cancer Center and recognized other families from

their neighborhood.

State and local health agencies keep track of higher-than-usual disease reports, but there isn't a central location that keeps track of local reports, making it difficult to look for broader trends. Even those who are part of a possible cluster are often unaware that others in their community are experiencing the same disease.

Panel chairwoman Sen. Barbara Boxer (D-Calif.), introduced a bill -- along with Republican Sen. Mike Crapo of Idaho -- that would increase coordination between federal agencies to investigate potential disease clusters.

The Senate panel also heard from Erin Brockovich, who was made famous by the 2000 film bearing her name. "Erin Brockovich" starred Julia Roberts and depicted hexavalent chromium poisoning in the town of Hinkley, Calif., allegedly caused by the Pacific Gas & Electric Company.

In real life, the company was ordered by a judge to pay a $333 million settlement, which was divided between 648 plaintiffs. Brockovich is now an environmental advocate who runs a consulting firm in California.

Also testifying was Trevor Schaefer, a 21-year-old who was diagnosed with malignant medulloblastoma, a form of brain cancer, at the age of 13. The same year Schaefer was diagnosed, there were four other brain cancers diagnosed in his small town of McCall, Iowa, which has a population of just 1,700.

Radiation in Boston rain linked to Japan nuclear crisis

U.S. slips behind China, Germany in clean energy

Mar 28, 2011

Report: 42 disease clusters in 13 U.S. states identified

By Wendy Koch, USA TODAY

Updated 2011-03-28 5:04 PM

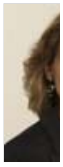
CAPTION By Reed Saxon, AP

At least 42 disease clusters have occurred in 13 U.S. states since 1976, according to a report Monday by environmentalists calling for further study of the cause of these health problems.

"Communities all around the country struggle with unexplained epidemics of cancers, birth defects and neurological diseases," report co-author Gina Solomon, a senior scientist at the Naural Resources Defense Council, said in announcing the findings. "The faster we can identify such clusters, and the sooner we can figure out the causes, the better we can protect residents living in the affected communities."

On Tuesday, the Senate Environment and Public Works

About Wendy Koch



Wendy Koch has been a reporter and editor at USA TODAY since 1998, covering politics and social issues. She's begun a quest to build the most eco-friendly home her budget allows. She'll share her experience and give you tips for greening your home. More about Wendy

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Committee has scheduled an oversight hearing on the issue. Among those testifying, aside from Solomon, are Trevor Schaefer, a 21-year old survivor of brain cancer from Boise, and Erin Brockovich, who became a household name when her fight to document a disease cluster in Hinkley, Calif., was turned into an eponymous movie starring Julia Roberts.

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Sens. Barbara Boxer, D-Calif., and Mike Crapo, R-Idaho, proposed legislation in January to fund research that would determine whether a connection exists between clusters of cancer, birth defects and other diseases and environmental contaminants.

The report, co-written by the National Disease Clusters Alliance, says Congress' Toxic Substance Control Act of 1976 has not studied that nexus or done enough to regulate toxic chemicals in industrial, commercial and consumer products.

The authors plan to identify disease clusters in all 50 states but focused their initial work -- using news reports, government research and peer-reviewed academic studies -- on 13 states: Texas, California, Michigan, North Carolina, Pennsylvania, Florida, Ohio, Delaware, Louisiana, Montana, Tennessee, Missouri and Arkansas.

They report a specific contaminant-- asbestos -- was identified in only one of the 42 clusters, which occurred in Libby, Mont. They say investigating the environmental causes of disease clusters is difficult, expensive and often inconclusive, partly because of limits in scientific tools for probing cause-and-effect in small populations.

In Hinkley, Cailf., for example, residents won a $333 million settlement from Pacific Gas & Electric in 1996 when the company's ponds leached hexavalent into the town's drinking water supply. They reported breast cancer, Hodgkin's disease, miscarriages and spinal deterioration, but three studies from the California Cancer Registry have concluded that cancer rates were not elevated there from 1988 to 2008. Other state officials say the population is too small for a cancer survey to yield meaningful results.

In a blog post Monday, Solomon cites several other disease clusters that she and other scientists documented:

- Birth defects in Kettleman City, California, including twenty babies born over less than two years with birth defects, and four children born with birth defects so severe that they have since died, in this town of only 1,500 people.
- Amyotrophic Lateral Sclerosis (Lou Gehrig's disease) – a very rare disease - in Herculaneum, Missouri, a town affected by a major lead smelter and decades of pollution.

- Multiple sclerosis (MS) in Wellington, Ohio, where residents are three-times more likely to develop MS than in the rest of the country, a disease whose causes are unknown but are thought to involve a combination of genetic and environmental causes.
- Birth defects in Dickson, Tennessee, a striking cluster that was identified by a non-profit organization called Birth Defect Research for Children, created by the mother of a child with birth defects, which gathers information about birth defects nationally, links families, and works with scientists to identify patterns that require investigation.
- Male breast cancer, childhood cancer, and birth defects in Camp Lejeune, North Carolina. More than 60 men who lived on that base have been diagnosed with male breast cancer – an extraordinary and alarming finding which is almost impossible to occur by chance alone, and one which deserves urgent attention.

"These examples are just the tip of the iceberg," Solomon writes. "In the states we haven't studied yet, we have already heard of dozens more disease clusters, so the problem is widespread."

See photos of: Florida, Congress, Texas, North Carolina, Ohio, Pennsylvania, Tennessee, Missouri, Louisiana, Arkansas, Montana, Delaware, Julia Roberts, Boise, Lou Gehrig, Camp Lejeune

TAGS: FLORIDA CONGRESS TEXAS NORTH CAROLINA OHIO PENNSYLVANIA TENNESSEE MISSOURI LOUISIANA ARKANSAS MONTANA DELAWARE JULIA ROBERTS BOISE NATURAL RESOURCES DEFENSE COUNCIL LOU GEHRIG CAMP LEJEUNE SENATE ENVIRONMENT AND PUBLIC WORKS COMMITTEE ERIN BROCKOVICH HERCULANEUM CAILFORNIA HINKLEY GINA SOLOMON HEXAVALENT CHROMIUM CHROMIUM-6 LIBBY, MONT. PACIFIC GAS & ELECTRIC CO.

Harris County cancer clusters get unprecedented extra study

Thursday, June 25, 2015

HOUSTON --

For the first time in a decade, Texas health officials are considering a deeper investigation of cancer clusters after determining that findings near the polluted San Jacinto River in eastern Harris County were "significant enough."

The Texas Department of State Health Services has published more than 260 cancer cluster investigations since 2004. But until now, the state has never recommended the next step of seeing if an epidemiologic study is feasible, the Houston Chronicle reported Saturday.

An initial state report identified several tracts near the river with greater-than-expected incidences of childhood cancers of the eyes, skin and brain. The report was designed only to determine if there is more of a specific cancer in an area than expected - and not to pinpoint causes.

"While these cancers are rare and few total cases were identified, the analysis determined that these findings are significant enough to warrant a discussion of whether additional study is feasible," state officials concluded in a report released this week.

The San Jacinto Waste Pits on the river's western banks hold toxic paper mill waste that seeped into the water for years, leading to several lawsuits. Residents who live nearby have spent years pointing to the site as a possible cause for the cancers.

Both state and federal officials say it is extremely difficult to link elevated cancers with any particular environmental exposure.

Epidemiologists found elevated levels of childhood eye cancer, known as retinoblastoma, in one Harris County census tract that includes Highlands. That town, which is near the waste pits, also had elevated levels of kidney and cervical cancer.

Another tract near Lake Houston had elevated levels of brain cancer. The state found 23 cases, where it expected to see 13.5. Seven cases involved children - roughly double the expected number. Researchers also found elevated childhood glioma, brain stem cancer, in a census tract north of U.S. Route 90 and east of Texas 8.

A neighboring census tract had double the expected number of childhood leukemia cases.

"We knew it was going to be bad, but holy cow," said Jackie Young, who grew up two miles from the San Jacinto Waste Pits.

Only a handful of residential cancer cluster investigations prompted by community concerns across the nation have resulted in the identification of an environmental trigger, according to a 2012 study led by an Emory University professor.

Chris Van Deusen, a spokesman for the state health agency, said the state is primarily focused on the elevations of childhood cancers, since adult cancer is far more difficult to study.

FlaglerLive.com

Childhood Cancer Clusters in Florida and The Department of Health's Lethal Silence

By Alan Farago

This is a story about pediatric cancer clusters in Florida. It begins in Durham, N.C., at Duke University, where Dr. David Banks is a professor in the Department of Statistical Science.

In 2013 Dr. Banks was the new editor of Statistics and Public Policy, a journal of the American Statistical Association. In early February, Banks gave a speech to the Florida Chapter of the ASA at the University of West Florida in Pensacola. There, he met with Dr. Raid Amin, a distinguished statistics professor at the university.Three years earlier, a team led by Dr. Amin had published a paper, "Epidemiological Mapping of Florida Childhood Cancer Clusters."

Dr. Amin's statistical analysis of pediatric cancers in Florida – from the years 2000 to 2007 – concluded that there are significant cancer clusters in two large areas of Florida: the southern region of Florida and in northeast Florida. That struck one of the most sensitive nerves in state government.

Its publication was lightly reported in the press, but to state officials charged with monitoring public health, it followed in the highly publicized wake of two claims of pediatric cancer clusters, one in Port St. Lucie in the 1990s and another in an unincorporated area of West Palm Beach called The Acreage in 2009. Even today, reading the plaintive cries for help from aggrieved parents is heart-wrenching.

Although the causes of pediatric cancer are poorly understood, the incidence of its most common forms – leukemia, cancers of the brain and nervous system, and lymphoma – are rising around the United States, according to the Centers for Disease Control and Prevention. As the incidence rises, so do public calls for some sort of accountability. In Florida, that particular responsibility falls to the State Department of Health.

In both Florida instances, Port St. Lucie and West Palm Beach, the Department of Health – the agency charged with registering data and investigating claims of cancer clusters – emphasized to the public that there was no identifiable cause and effect. As in the case of most claims about cancer clusters, the angst and public outcry generated media attention then blew out like a passing storm. Cancer strikes like lightning. It doesn't matter if it is adult or pediatric cancer, although the very mention of pediatric cancer makes me nauseous. According to the CDC, cancer is the leading cause of death by disease among children. For most people, when cancer strikes, it instantly becomes a full time occupation – from flights of hope, tumbles to despair and every step between where the mind can rest. There are no part-time victims of cancer.

In the midst of battling cancer, it rarely occurs – or seems irrelevant if it does – that one's personal or family catastrophe ought to be weighed as 1) a deviation from a statistical norm or 2) that there is something in the external environmental that caused the cancer, unless one begins to hear about other rare cancers in the neighborhood. Then, alarm bells go off like no others. (A cancer cluster is where a greater than expected number of cancer malignancies occur within a group, a geographic area, or a period of time.)

Dr. Banks and Dr. Amin are not in the cause-and-effect end of cancer. Statistics is the practice or science of collecting and analyzing numerical data in large quantities. The idea is that you take a big soup of numbers, strain it, analyze what's in the numbers and infer proportions from a representative sample. It is a practice that can be applied over any kind of dataset – from growing nuts to assembly of microchips.

In an interview, Dr. Banks told me that after visiting the University of West Florida, he was intrigued. Are there cancer clusters in Florida or not?

The 2010 report, covering data from 2000 – 2007, states that "… during this time, there were 4,591 cases of pediatric cancer diagnosed, of which 1,254 (27 percent) had leukemia, 839 (18 percent) had brain/central nervous system (CNS) cancer, and 252 (5.5 percent) had lymphoma."

In south Florida, the cluster encompasses the southwest, south central and southeast regions where "… compared with the state, there is a statistically significant 36 percent increased risk of childhood cancer." Also, "In the northeast Florida cluster, there were 466 and 375 observed and expected cases, respectively. This region appears to be smaller in size, although it may represent a more densely populated area. … In addition, a third overall childhood cancer cluster

was identified in a small area of central Florida in which the observed number of cases was 31 as compared to 11 expected cases. The rates were statistically significantly higher in this area relative to the state … which implies that compared with the state of Florida, those in this area are almost three times as likely to be diagnosed with childhood cancer."

Following its publication, in March 2010 Dr. Amin and his colleagues were invited to Tallahassee by the Surgeon General of Florida, state health officials and the CDC to discuss their findings. In an interview, Dr. Amin told me, "It was a chilly meeting." At the time, a state health official told the Palm Beach Post that the report's analysis methods were "relatively new and untested" and that "independent researchers will use this report to identify areas that require additional study using more traditional methods."

A few weeks later, the Florida Department of Health told Dr. Amin that the agency's data sets including pediatric cancers did not match the Florida researchers'. According to Amin, "They promised to share their data if we gave them ours. We gave them our data, and they never gave us theirs."

For the ensuing three years, after the publication of their paper in Pediatric Blood Cancer, silence.

Fast forward to February 2013, when Duke professor David Banks met professor Raid Amin at the University of West Florida. "Since I had just started as the publication editor, we were looking for interesting projects," Dr. Banks told me in an interview. During the meeting Dr. Banks and Dr. Amin discussed a study Amin and colleagues had recently completed on clusters of adolescent and young adult thyroid cancers in Florida counties.

Banks said it would be an interesting idea to update the earlier 2010 study and have other statisticians review the data and conclusions. In other words, apply independent methodologies on the same data to ask the question: are there cancer clusters in Florida?

Amin said he would need to check if he could share the data, and a few weeks later informed Banks it would be okay to proceed. Banks "started to contact some of the statisticians (he) knows who are prominent and work in epidemiological statistics. Some were busy and declined, others were interested in the experiment of having multiple papers on the same data, and eventually I obtained five papers (one by Dr. Amin). These all went through peer review, and after revision were ultimately published. To the best of my knowledge, there were no previous peer-reviewed papers comparing different methods on the same data."

On May 29, 2014, Dr. Amin and colleagues published their updated paper reviewing pediatric cancer data covering the 11-year period from 2000-2010. Dr. Amin's report identifies two pediatric clusters – in the Miami metro area and an area nearby, west of the Everglades around the

southern portion of Lake Okeechobee. The cluster analysis results for the three cancer types and the total cancer rates are similar to what Amin and colleagues had concluded in 2010. “The three most widely recorded pediatric cancer types all occur in a geographical area that is close to Miami and to Lake Okeechobee. The relative risk values are not small, indicating cancer rates that are higher than what is found in other parts in Florida by 35 percent –52 percent.”

A year later, on April 17, 2105, the American Statistical Association published its review of the same data. “The process followed the usual academic path. It takes a long time to do,” Dr. Banks said. “Each of the five teams that took on this project, submitted drafts to peer review. Each paper had two referees to review the work, and some of the papers went through a few rounds of revisions. It is the first time we had done something like this.”

Five separately conducted methodological assessments, summarized by Dr. Lance Waller, a biostatistics professor specializing in spatial epidemiology at Emory University in Atlanta, confirmed Dr. Amin and colleagues’ findings: “The five author groups find some consistent results: there seem to be local areas where the observed cancer rate is statistically significantly higher than we would expect and the different methods tend to identify a few common areas. As noted above, the clusters themselves are not identical, but they do overlap. …”

For Dr. Amin, five years have passed since he and his team alerted the state to the presence of cancer clusters in Florida, but the memory is still vivid.

Not as vivid, of course, as the memory of anyone who suffered through a child’s cancer.

In 2010, when the state of Florida contested Dr. Amin’s data, a state health officer recommended that Amin and his colleagues contact the journal in which the paper had been published. Amin was troubled. “We saw no errors (in our data), and we suggested to them that research is not done that way. If you (the state) think you found errors, then you write the editors and you provide the correct data and results. They never did.”

I recently submitted two questions to the Florida Department of Health: 1) In a recent journal of the American Statistical Association, Dr. Lance Waller summarized the results of five independent statistical analyses of cancer data in Florida. What is the DOH response to that report? 2) Pediatric Blood Cancer 2010 published an earlier study, “Epidemiological Mapping of Florida Childhood Cancer Clusters.” What was the DOH response to that article at the time, and has the position of DOH changed or is it the same?

In response, I received the following statement: “The Florida Department of Health cannot comment on the two studies mentioned as we have not had adequate time to review.”

This August in Seattle, at the upcoming meeting of the American Statistical Association, Dr. Amin will discuss his research in a special session titled, “Are there cancer clusters in Florida?”

US National Library of Medicine National Institutes of Health

High soil and groundwater arsenic levels induce high body arsenic loads, health risk and potential anemia for inhabitants of northeastern Iran.

1. Department of Geology, Ferdowsi University of Mashhad, Mashhad, Iran.

Abstract

Arsenic bioavailability in rock, soil and water resources is notoriously hazardous. Geogenic arsenic enters the body and adversely affects many biochemical processes in animals and humans, posing risk to public health. Chelpu is located in NE Iran, where realgar, orpiment and pyrite mineralization is the source of arsenic in the macroenvironment. Using cluster random sampling strategy eight rocks, 23 soils, 12 drinking water resources, 36 human urine and hair samples and 15 adult sheep urine and wool samples in several large-scale herds in the area were randomly taken for quantification of arsenic in rock/soil/water, wool/hair/urine. Arsenic levels in rock/soil/water and wool/hair/urine were measured using inductively coupled plasma spectroscopy and atomic absorption spectrophotometry, respectively. While arsenic levels in rocks, soils and water resources hazardously ranged 9.40-25,873.3 mg kg-1, 7.10-1448.80 mg kg-1 and 12-606 µg L-1, respectively, arsenic concentrations in humans' hair and urine and sheep's wool and urine varied from 0.37-1.37 µg g-1 and 9-271.4 µg L-1 and 0.3-3.11 µg g-1 and 29.1-1015 µg L-1, respectively. Local sheep and human were widely sick and slightly anemic. Hematological examination of the inhabitants revealed that geogenic arsenic could harm blood cells, potentially resulting in many other hematoimmunological disorders including cancer. The findings warn widespread exposure of animals and human in this agroecologically and geopolitically important region (i.e., its proximity with Afghanistan, Pakistan and Turkmenistan) and give a clue on how arsenic could induce infectious and non-infectious diseases in highly exposed human/animals.

Incidents of cancer clusters evident worldwide

Frank X. Mullen Jr.
Reno Gazette-Journal
January 29th, 2001

Cancer and leukemia clusters have sprung up all over the industrialized world during the last 50 years but epidemiologists say few of the cases can positively be linked with a contaminant.

Accidents are the most common cause of child deaths in the United States, but cancer is the second-largest killer of children, according to the National Cancer Institute and the National Childhood Cancer Foundation.

While some cases coincide with the presence of a known carcinogen in the drinking water or elsewhere in the environment, connections are hard to prove, scientists say.

Dr. Alexander Aledo, a leukemia specialist at New York Weill-Cornell Center in Manhattan, N.Y., said people are always wanting to pin the blame on something, but in the vast majority of cancer clusters the environmental causes — if they exist — remain unknown.

"Connections aren't easily made," he said.

Here's a look at some high-profile cancer/leukemia cluster cases:

In Tom's River, N.J., 103 children are part of the nation's largest child cancer cluster. State environmental officials discovered 4,500 drums of toxic liquid had been dumped in a nearby landfill and at a local farm. Still, it's difficult to prove the leukemia cases are directly caused by the pollutants.

In the Woburn, Mass., cancer cluster, made famous by the book and movie "A Civil Action," 21 children contracted leukemia. The culprit was believed to be drinking water contaminated by a hazardous waste deep-injection well. Eight families got $400,000 in the settlement of a civil suit that ended in 1986. Some scientists argue that the link between the contaminated wells and the leukemia patients was not strong enough to entirely explain the "excess" leukemia.

In La Hague, France, 27 cases of leukemia were diagnosed in people under 25 years of age between 1978 and 1993. The area is home to the world's largest nuclear reprocessing facility. Scientists have made a case for radioactive contamination of the ocean and the sea animals and have found that victims who spent time at the beach or who ate seafood appeared more likely to contract leukemia.

In Britain in 1983, scientists began noticing a 10-scale increase in leukemia cases in the village of Seascale. The "Seascale Cluster," as it became known, has been extensively studied by scientists. The village is near the Sellafield nuclear processing facility, but discharges from that plant seem to be too low to account for the increase in childhood leukemia, according to a 1984 study. A second study, which remains controversial, links the fathers' exposure to radiation before conception of children to childhood leukemia.

Another British researcher has suggested that when urban areas mix with people from rural communities — as happened in Seascale — exposure to viruses increase. That theory lends support to another British scientist's idea that some unknown infection causes leukemia clusters.

Studies conducted after the Seascale Cluster investigations found a slight, but significant increase in leukemia in people under the age of 25 in the areas around 15 nuclear facilities in England and Wales.

A cancer cluster in the early 1990s in Hinkley, Calif., inspired the movie "Erin Brockovich." In that case, Pacific Gas and Electric went to private arbitration with the 650 plaintiffs and paid $333 million. The case involved chromium from the utility winding up in the residents' well water.

In 1984 cancer cases began popping up in McFarland in California's Central Valley. During a 20-year period, 21 people, mostly children, were diagnosed in the town of 8,000. A state study from 1985-1991 ended inconclusively and the Environmental Protection Agency was petitioned to study the problem. Residents suspect airborne pesticides but no causal link has been found.
Randall Todd, Nevada state epidemiologist, has said it's rare that scientists can trace the cause of cancer clusters.

"It's very difficult to find a smoking gun," he said.
But he said the Fallon leukemia cluster remains the health division's top priority and investigators are looking into many theories for the unexpected concentration of leukemia cases.

delawareonline

April 24, 2008

Cause of cancer clusters often never discovered

Toxins generally cause rare forms of disease

By HIRAN RATNAYAKE
The News Journal

Genuine cancer clusters account for only a small number of suspected clusters, said Tim Aldrich, an epidemiologist who has studied disease clusters across the nation for three decades.

And even in those cases, the actual cause of a cluster often is never discovered.

One of the best-known cases of a bona fide cancer cluster, Aldrich said, occurred in the mid-1990s at Toms River, N.J., where there appeared to be pediatric cancer clustering. Toms River is adjacent to two "Superfund" sites, designated as high priorities for cleanup by the Environmental Protection Agency because of the presence of hazardous waste.

A study over several years concluded that no single risk factor was responsible for the elevated level of childhood cancer in that region.

Environmental toxins generally cause a specific, rare cancer, experts say. Vinyl chloride monomer, for example, has been found to elevate the risk of hepatic angiosarcoma, a rare liver cancer.

"We tell students common things happen commonly and rare things happen rarely," said Aldrich, an associate professor of epidemiology at East Tennessee State University in Johnson City, Tenn.

"The meaningful clusters are the result of something really bizarre and very strange becoming more common."

The eight areas in Delaware identified by the state's Division of Public Health as having cancer clusters do not show a cluster of any rare cancers. The clusters identified include prostate, lung, colorectal and all cancers.

The next step in Delaware, Aldrich said, is to monitor the region for the next three to five years.

"You want to just keep watching the community to see if something changes," he said.

When clusters warrant increased surveillance, local universities typically apply for grants to do further study. Ideally, researchers want to compare the population with the cluster to a similar community to see if something sticks out.

"Sometimes you never figure out what it is," Aldrich said.

Dr. Jaime Rivera, director of the Delaware's public health division, said it would cost millions of dollars to do an in-depth study of the environmental factors.

People who live in poor socioeconomic areas where a cluster appears may actually have higher cancer rates because of other risk factors. People in poverty are more likely to live near power plants. But they're also more likely than the general population to smoke and be obese and in worse physical shape.

All those are risk factors for cancer, said Dr. Michael J. Thun, vice president for epidemiology and surveillance research at the American Cancer Society.

"It's always the case that cancer rates are distributed unevenly," he said, "and almost always, they relate strongly to socioeconomic factors."

Another difficulty in making the link is that cancer risks from environmental causes take several years to make their effect apparent. Cancer in the colon, Aldrich said, "isn't going to go from a pinhead size to a golf ball size in less than five years."

The Palm Beach Post

Updated: 11:07 p.m. Monday, Sept. 13, 2010 | Posted: 3:26 p.m. Monday, Feb. 1, 2010

New data confirms Acreage cancer cluster; health officials puzzled on cause of children's ailments

Related

By Mitra Malek

Palm Beach Post Staff Writer

THE ACREAGE — The Acreage has a cluster of childhood cancer cases, the head of Palm Beach County's Health Department said Monday, confirming some of the worst fears of parents who called for a state investigation last year.

Eight months of uncertainty ended Monday when state health officials confirmed that rates of brain tumors and brain cancer among children in the semirural community are higher than normal, especially among girls.

But based on early results of interviews with the families, it's unlikely that health officials will be able to pinpoint what has caused the spike, said Dr. Alina Alonso, director of the county's Health Department, a division of the state health department.

"We really don't have one thing," Alonso said during a monthly conference call updating legislators on the investigation, which started in June. "From what we're seeing now, there is nothing that is going to say, 'Aha this is the cause of the cancer.'"

Health officials recently completed interviews with 12 of 13 families with children who have been diagnosed with either brain tumors or brain cancer from 1993 through 2008, in search of commonalities. One of the 13 families couldn't be located because they moved.

Until the department finishes analyzing those interviews in the next two months, the state wouldn't conduct any environmental tests, if at all, to look for a potential cause, said county health department spokesman Tim O'Connor.

Even so, O'Connor added, Alonso has said that the data available so far are enough to label the cancer cases a cluster.

Officials plan to discuss the investigation at a public meeting from 6:30 to 8:30 p.m. Feb. 9 at Seminole Ridge High School.

Residents said they were somewhat relieved to hear there is a cluster. But they said environmental tests are imperative.

"It makes us feel a little better that we're not crazy," said Greg Dunsford, whose 7-year-old son had a tumor removed in 2008.

Still, "if you know there's a problem out there, would you not spend every ounce of energy to find out what it was?" added Dunsford, whose wife requested the state study. "Just because they can't find it doesn't mean it's going to go way."

Two more children were diagnosed with brain tumors in late 2009, stoking residents' fears that the cluster will keep growing.

"For everybody to have a comfort level, you need to know the source," said Michelle Damone, board president of the Indian Trail Improvement District. "Without knowing the cause of it, how do you go and correct it?"

At least one affected parent said she understands health officials' plight in identifying a cause.

"Everybody is exposed to a multitude of things," said Becky Samarripa, whose 15-year-old daughter had a tumor removed in 2008. Still, so many of these children went to the same schools, play in the same soil and drink well water that tests in at least one of those areas should be warranted, she said.

Based on samples taken randomly from 50 Acreage homes last year, the state Department of Environmental Protection concluded that some homes have wells with elevated levels of radium and other radioactive substances that could result from natural causes. Excessive radiation can cause brain cancer.

The same DEP study concluded that ground water quality in The Acreage is "generally good."

Even if the state doesn't turn up answers, many residents are hanging hope on a New York law firm affiliated with environmental activist Erin Brockovich. Weitz & Luxenberg has been conducting water analyses since late last year. Some show elevated radiation levels.

Confirmation of the cluster came after health officials considered updated population data.

In preliminary findings released last August, the state had said there appeared to be a brain cancer cluster in children or teenagers up to 19 years old in The Acreage. But that conclusion was based on numbers from the 2000 U.S. Census, when the population was smaller — possibly making the cancer rates look incorrectly elevated in comparison.

The new data showed that 32,000 to 40,000 residents live in The Acreage, while health officials had originally estimated 29,000 people live there.

Despite the growing population, the childhood cases diagnosed in the community would still be considered abnormally high, health officials said.

If you go

What: Palm Beach County health officials plan to discuss their interviews and population research at a public meeting.

When: 6:30 to 8:30 p.m. Feb. 9.

Where: Seminole Ridge High School, 4601 Seminole Pratt Whitney Road, Loxahatchee

Title: Pollution Linked to Childhood Leukemia
Author(s): Maia Davis and Bob Groves
Source: The Record, 12/19/2001
AN: 2W62209009372

Pollution Linked to Childhood Leukemia

Dec. 19--DOVER TOWNSHIP, N.J.--Confirming what many residents of this Ocean County town long suspected, state and federal scientists announced Tuesday they had found a link between exposure to certain water and air pollution and some childhood cancers.

Scientists stopped short of declaring that pollution caused the Toms River cancer cluster, named after a section of this town.

"Chance remains a possible explanation for some or all of these findings," said the principal investigator, Dr. Jerald Fagliano of the state Department of Health and Senior Services.

But officials said the study, part of a six-year investigation that cost more than $10 million, is one of the most thorough probes ever done linking environmental pollution to cancer in children.

The study found that young girls whose mothers, while pregnant, lived near a former Ciba-Geigy chemical plant and may have been exposed to its air pollution were 19 times more likely to get leukemia than other girls in the township.

Girls whose mothers drank tap water from a particular contaminated public well were six times more likely to get leukemia, the study found.

State officials said the study found no connection between pollution and other types of cancer.

New Jersey began its investigation after finding that between 1979 and 1995, 90 of the town's children developed cancer, a significantly higher rate than the rest of Ocean County or the state.

Since then, 28 more children in the township have been diagnosed with cancer, said Linda Gillick, the mother of a cancer victim who helped spearhead the call for a government investigation. Of the 118 children, 16 have died, she said. State officials couldn't confirm how many had died.

The town's children had particularly high rates of leukemia and cancers of the brain and central nervous systems, which are usually rare.

The research left many questions unanswered, including: What accounted for the high rates of cancers of the brain and nervous system and why is there a stronger link between pollution and leukemia in girls than in boys?

But Gillick said she was "not dissatisfied" with the findings.

Gillick, whose 22-year-old son, Michael, suffers from neuroblastoma, a central nervous system cancer, said state and federal officials put their best efforts into the study. She echoed scientists in saying that more studies need to be done on the possible connection between pollution and cancer.

"I have grandchildren now in this town and I want them protected," she said.

Soon after the release of the report Tuesday, leukemia patient Eric Kaari, 26, said he suspected something was wrong in Toms River years ago while being treated at Sloan Kettering Cancer Center in New York.

"When the nurses ask you where you're from, you say, 'You might not have heard of it, it's a small town, Toms River, New Jersey.' They say, 'Oh, you're from there, too?' " he said.

Jan Schlichtmann, the Massachusetts attorney helping the Toms River families, said the study proves parents' contention that pollutants caused their children's cancer.

"The numbers tell a very dark story," he said. "We have to acknowledge that chemicals -- even in tiny amounts -- can profoundly influence public health.

"This study . . . will have vast implications for how this country deals with toxic waste," he said.

Juan Reyes, of the federal Agency for Toxic Substances and Disease Registry, which conducted the study with the state, said scientists know little about the causes of childhood cancer. "We do know there's been a 30 percent increase in childhood cancer over the last three decades," he said.

The nation has also seen a 40 percent increase in brain and central nervous system cancers in the past three decades. He said the federal government is studying the possible cause of this rise in four states with high rates of these cancers -- New Jersey, New York, Pennsylvania, and Florida.

State officials stressed that measures have been taken to stem pollution in Dover Township. The former Ciga-Geigy dye manufacturing plant, which caused both air and water pollution, has been shut down and is a federal Superfund site. The name of the company has been changed to Ciba Specialty Chemicals Corp.

The Parkway Well, linked to a high rate of leukemia, has new treatment systems to remove chemicals from the water. It is one of a number of public wells in the town.

The Parkway Well was contaminated after Union Carbide Corp. illegally dumped 4,500 drums of chemical waste at nearby Reich Farm in 1971. An underground plume of chemicals flowed from the farm, which is also a Superfund site, to the well.

Besides the Parkway Well and air pollution from Ciba, investigators also examined other potential sources of pollution, including a second contaminated well, a nuclear power plant, and private wells.

The study found that:

Boys and girls in areas with private wells were more likely to have leukemia, though the overall number of these cases was small.

Girls who lived within one half-mile of the Ciba pipeline had a higher incidence of leukemia.

Girls under 20 were six times more likely to develop leukemia if their pregnant mothers regularly drank tap water from the Parkway Well from 1982 to 1996. When they shortened the time frame to 1984 to 1996, the likelihood of girls developing leukemia increased to 15 times above other girls.

Girls under 5 were 19 times more likely to get leukemia if their mothers lived near the Ciba plant, exposing them to air pollution while they were pregnant.

The study showed no links between cancer and the other potential sources of pollution.

Scientists did the study with sophisticated computer models that have attracted interest around the world, Reyes said. The models estimated, for example, how much tap water from polluted wells flowed into each household studied during every month from 1962 to 1996. Computers also figured how much air pollution spread from the Ciba plant over the same period.

Investigators compared birth records showing year and place of birth of children who developed cancer with others in the town who stayed healthy. They also interviewed parents of 199 township children, including 40 who had cancer.

Last week, Ciba Specialty Chemicals Corp., Union Carbide, and United Water-Toms River, which bought the public water system serving most of the township from Toms River Water Co. in 1994, agreed to confidential cash settlements with 69 families with stricken children. They admitted no responsibility.

Rich Henning, a spokesman for United Water, said the company was reviewing the study, but maintains it is not at fault. "We do not believe the study concludes that there's an association between our water and childhood cancer," he said. "The study certainly doesn't point out any conclusive evidence."

Donna Jakubowski, a spokewoman for Ciba Specialty Chemicals, said she had seen only a preliminary summary of the study. But she said that "the bulk of the report should be interpreted cautiously."

"There was a considerable level of uncertainty in their modeling" of air pollutant data, Jakubowski said.

Union Carbide Corp., which has taken responsibility for the Reich Farm, has long denied responsibility for the illnesses.

For some parents in Toms River, the report was a disappointment after so many years spent waiting for answers. Bruce Anderson, whose son, Michael, developed a rare form of leukemia at age 10, believes the research should have been more extensive.

"With the amount of money they spent on it, they could have done a more thorough job," he said.

Michael Anderson, now 20, is still receiving treatment for effects from three years of chemotherapy. "You're never out of the woods with this" disease, the father said.

Last week's settlements also offered little comfort.

"I'd give all the money back to get [Michael's] health back," he said.

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Source: The Record.
Item Number: 2W62209009372

Toms River Still Asking A Question: 'Why Us?'

By IVER PETERSON
Published: December 24, 2001

TOMS RIVER, N.J., Dec. 21— For years, the children suffered and died from cancer while their parents pleaded for answers.

Common sense told them that the unusually high level of childhood cancers in Toms River and surrounding Dover Township had been caused by chemicals from two Superfund sites that had gotten into the water they drank and the air they breathed. For years, they organized parents' groups, wrote letters and lobbied in Trenton and in Washington for money and action.

After a six-year, $10 million study, science gave them their answer: Of all the cancers, only childhood leukemia in infant girls may have been statistically associated with chemical pollution.

The epidemiological report, released on Dec. 18, could offer no explanation for the array of other childhood cancers -- the brain cancers, the spinal melanomas, the neural blastomas -- whose concentration here frightened residents and contributed to New Jersey's reputation as one of the country's venomously polluted cancer alleys. After so many years of waiting, the results left many parents on an emotional fence, drained of anger and glad for a partial vindication but wishing that science could have provided a clearer reason why.

But then, these are parents used to disappointment.

"I'm glad they did find something, because so often these studies don't find anything," said Joseph J. Kotran, who gave up his real estate business to stay home with his 5-year-old daughter, Lauren Marie, who is struggling with the effects of neural blastoma, a cancer of the central nervous system. "But we are disappointed that they didn't speak to the other children."

With only a partial vindication, parents are stuck with defending the common-sense

hunches, said Linda Gillick, a leader in the township's fight to win official attention for its plight and the founder of a children's cancer support group called Ocean of Love.

"You can't have a child with leukemia living two houses down from a child with a tumor, drinking the same water and breathing the same air, and tell me they didn't get cancer from exposure," Ms. Gillick said. "That's my common sense speaking."

For all their disappointment, the parents of Toms River have a success story to tell, compared with a dozen or more other places around the country, in Louisiana, in Illinois and in Nevada among other states, where parents have counted the cancers and pointed a finger at nearby refineries, uranium processing plants and chemical factories. Here, parents created the political furor that awakened state and federal agencies and New Jersey's Congressional delegation, winning the years of studies and testing that culminated in the just-released final report.

Now some of the state's politicians seem to be more upset with the results than the parents themselves. James B. McGreevey, the governor-elect, strongly attacked the State Department of Health and Senior Services for taking so long before acknowledging that a problem existed here and before coming in to close the wells, install monitoring equipment and begin the scientific sleuthing.

Senator Robert G. Torricelli, who, with Representative Jim Saxton, the district's representative in Congress, kept pushing for money to pay for the study, simply expressed disappointment that the results could not go further.

"I feel vindicated that our suspicions about childhood cancer being related to extreme environmental problems have been proven accurate," Mr. Torricelli said in an interview after the report was released. "But it's frustrating that the rest of the problems cannot be identified."

From the outset, Dover Township, which has a population of more than 76,000, was up against a federal cancer study protocol that counts only the frequency of a single cancer when determining whether a statistically significant cluster is present. A 1996 study found that the township had 97 cases of childhood cancer over a 14-year period when the normal number should have been 60, but only childhood leukemia, one of the most common of childhood cancers, was present often enough to constitute a cluster linked to industrial pollution.

The theory is that similar causes should affect its victims alike, but Ms. Gillick, for one, contends that the theory flies in the face of logic. "We do not know what causes the different cancers," she said, "so there is a fallacy when they only look at certain types and not ask, when you're talking about all the different types we've seen, if they become statistically significant."

The parents' letdown has been softened by a financial settlement negotiated between 69 families with children with cancer and two chemical companies, Ciba-Geigy Inc. and the


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Union Carbide Corporation, and United Water Resources Inc., a private company that operates the Toms River water system.

The settlement, whose details have not been made public, came earlier this month just before final epidemiological report was released. But there are still more than 600 plaintiffs' lawsuits still pending against Ciba-Geigy and the water company, accusing them of a range of offenses, from causing cancers in adults to diminishing real estate values.

The epidemiological findings said that there was a possibility that air pollution from the old Ciba-Geigy plant, now closed, might have contributed to the childhood leukemia in girls, but the report was so hedged with qualifiers that the company reacted favorably to it.

"Obviously we still have to study the report thoroughly," said Donna Jakubowski, a spokeswoman for Ciba-Geigy. "But based on what was said to us and to others, we believe that our site has not had any impact on the community."

There does not seem to be much in the study to bolster the cases of the people who are suing Ciba-Geigy and the water company, said Michael L. Rodburg, Ciba-Geigy's lawyer. "In most respects, we're rather satisfied with the report," Mr. Rodburg said.

Kim A. Pascarella, a lawyer whose 14-month-old daughter, Gabrielle, died of a neurological cancer, said that he would accept the report, whatever its shortcomings. Rather than complain, Mr. Pascarella focused on the success of the community's grass-roots movement to get the attention of federal and state doctors and epidemiologists.

"The public outcry was the biggest thing," he said. "With the two Superfund sites being in such proximity to so many residents, we were able to convince the government agencies that they needed to take action." Now, Mr. Pascarella and other parents said, it was up to similar communities in other parts of the country to organize and to press for attention.

But study or no study, he does not plan to change his explanation of why Gabrielle died.

"I feel as strongly about it today as I ever have," he said. "I don't have scientific proof at this point, but in my mind I don't have any doubt that her death was caused by this contamination."

Photos: Children's cancers have rallied a community spirit in Toms River, N.J. Ocean of Love, a support group, and firefighters delivered presents to young patients like Brandon Delaney, above center. Joseph J. Kotran, left, gave up his business to care for his daughter, Lauren Marie, 5. (Emile Wamsteker for The New York Times); (Keith Meyers/The New York Times)

Firms Settle With Parents Of Ill Children

By IVER PETERSON
Published: December 14, 2001

A group of parents in Toms River, N.J., whose children were stricken with cancer have reached a monetary settlement with two chemical companies and a water utility that they accused of causing the disease through pollution, lawyers for the two sides announced yesterday.

The agreement, in which the companies did not acknowledge any responsibility for the cancers, ends four years of negotiations in a case that contributed to the national lore about New Jersey as an environmentally damaged state. None of the parties would disclose the size of the settlement, or how it would be divided among the families.

In all, 69 families, each with a member who developed cancer in childhood, will share the payments from the companies: Union Carbide Corporation, Ciba Specialty Chemicals Corporation and United Water Resources Inc., a private company that distributes water in the area. Sixteen of the ill young people have died since the first alarms about a high incidence of childhood cancer were raised in Dover Township more than 10 years ago.

"The way I look at it, if we can just prevent one other child from getting cancer, it will have been worth it," said Bruce Anderson, a computer specialist whose 20-year old son, Michael, was found at 10 to have leukemia. "We mustn't just look at our own families."

Hundreds of other Dover residents are suing the chemical companies over pollution or cancer. Those cases are not affected by the settlement.

The Toms River agreement is unusual not only in the cooperative way it was reached -- through negotiation and mediation rather than a lawsuit -- but also in the way the companies settled without the existence of proof that pollution they caused or distributed

through the water system was responsible for the cancers.

While the companies stressed today that no concession of responsibility was made, Linda Gillick, whose 22-year old son, Michael, developed a neuroblastoma at three months, maintained that the settlement was nevertheless about guilt.

"Even though the companies will not admit liability, if they make a payment, that says something to the rest of us," Ms. Gillick said. Donna Jakubowski, a spokeswoman for Ciba Speciality Chemicals, maintained that her company had settled to give the families some peace, not as an admission of responsibility.

"There has been no evidence that we were responsible," Ms. Jakobowski said. "Ultimately everyone agreed that by settling this case, we would bring closure for everyone. For Ciba, it means that we can focus on our ongoing remediation here at the site."

So far, only a 1996 report by the State Department of Health and Senior Services found an increased incidence of certain childhood cancers in the Ocean County area, without attributing responsibility to the water company or to two Superfund sites tied to the two chemical companies. But the final results of a more rigorous study will be released by the health department on Tuesday.

Steven Fineman, a lawyer who helped the parents, said the settlement was reached without regard for what that report might say, but the prospect of the state settling the question of the companies' responsibilities, once and for all, did hang over the negotiations, he said.

"Surely, when we were negotiating we knew there were people working on the study, but we didn't have any knowledge of what they were going to find," Mr. Fineman said. "But even if the study comes back and shows a positive relationship between certain children's cancers and certain chemicals, that doesn't necessarily mean that it would have advanced the cases of all 69 families, because different children experienced different kinds of cancers at different times."

Mr. Anderson, one of the parents, was philosophical about the importance of the money settlement.

"Am I satisfied?" he said. "I look at it as relative. We are a mixture of families: some have lost children, some are undergoing treatment, some have other medical problems coming in the future. So you really can't put a price on it."

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Go to Complete List

Cancer and Industrial Pollution

An ongoing investigation by the Socialist Equality Party

Return to Record of the Workers Inquiry

Childhood cancers linked to factory pollution

British study exposes BHP's lies

Children born near factories which are sources of industrial pollution are more likely to die of leukaemias and other childhood cancers before they reach adulthood, a major British study has found.

Researchers examined the cases of 22,400 children who died between 1953 and 1980 in one of the largest studies of childhood cancer carried out in Britain. They concluded that those born within 5 km of a source of industrial pollution were at a 20 percent higher risk.

The highest death tolls were associated with being born close to oil refineries, car factories, power stations, steelworks, cement works and crematoria. Place of birth was more important in determining the level of risk than the addresses to which children moved later in life.

Professor George Knox and other members of the Department of Public Health and Epidemiology at the University of Birmingham, who conducted the study, said the key pollutants appeared to be petrol fumes and similar volatile organic compounds and those produced by high temperature furnaces and kilns.

The research also showed extra cancer deaths among children born within 4 km of a motorway or railway, although beyond this distance there were fewer deaths than expected. The link between road and rail is likely to be petrol and diesel fumes, the authors say.

The researchers plotted the postcodes for the birthplaces of children who had died and compared their proximity with different types of industrial plant. Petrol stations, bus stations, hospital and school chimneys could also be dangerous, they said. Certain industries such as brewing, cotton manufacture and furniture building produced no correlation.

Professor Knox said the exposure of pregnant women or infants directly to airborne pollutants was the most likely cause of the excess cancer cases. These substances also combined to form secondary pollutants.

Knox said the 20 percent increase in risk was statistically significant because of the large numbers involved in the study. His study is published in the April issue of the Journal of Epidemiology and Community Health.

The findings, which held true across many different regions of Britain, shed new light on an earlier study which showed that the childhood cancer deaths tended to occur in small geographical clusters.

Some scientists have suggested infection may be the cause of childhood leukaemias as the building of new factories draws workers into an area, exposing the local population to new viruses.

Knox said that although infection could be a factor, it did not explain persistent excesses of cancer cases over many years which pointed to a local environmental hazard. "It is the only possible explanation," he told the British press.

BHP and benzene

This conclusion is highly significant to the Wollongong leukaemia and cancer crisis for a number of reasons.

In the first place, it further undermines the Illawarra Public Health Unit's claim that the leukaemia cases are simply an isolated "cluster" with no connection to the wider pattern of cancers and other ill-health caused by industrial emissions.

Secondly, the Unit's director, Dr Victoria Westley-Wise, indicated at the last meeting of its "community reference group" that its preliminary report on the leukaemia deaths will recommend a further study of the impact of "mixing populations" on exposure to unfamiliar viruses.

This proposal is a crude attempt to divert attention away from industrial pollution and to sow divisions among working class families, along the lines that immigrants and other new arrivals in the region were responsible for the deaths.

The British study shows that the leukaemias and cancers in Wollongong are likely to be the result of patterns of exposure to emissions of benzene and other known carcinogens, not isolated "clusters" caused by "alien" viruses.

It adds weight to the results of the preliminary investigation conducted by Workers News which found that people living close to the Port Kembla smokestacks were three times more likely to contract cancer than those living 20 km away. Our investigation used a similar methodology to the British study - plotting the postcodes of cancer patients compared with distance from the BHP steelworks and former Southern Copper smelter.

As part of an official cover-up, the NSW Cancer Registry has for years refused to provide postcode-by-postcode lists of cancer cases.

The British research also exposes the lies being peddled by BHP in its public statements in recent weeks. In a series of media releases, paid advertisements and staff briefings, BHP has claimed that there has been no demonstrated risk of leukaemia resulting from exposure to benzene emitted from gas processing plants around the world, including the plant at the Port Kembla steelworks.

The truth is that benzene, a by-product of the steelworks coke-making process, has been known for more than a century to be a leukaemia and cancer-causing toxin. American and other international scientific and medical studies have shown that coke ovens and gas processing plant workers have a far higher death rate from many cancers, including lung, kidney, larynx, pancreas and stomach, as well as leukaemias.

BHP claims that monitoring between September 1996 and January this year showed the level of benzene in the atmosphere in Wollongong's southern suburbs to be below recommended levels. But coke ovens workers have told the Committee for a Workers Inquiry that BHP has deliberately rigged the results by placing coke ovens on suction and by reducing the output from its dirtiest battery, Number 3, during monitoring, vastly reducing emissions.

In addition, BHP's figures are based on averages which disguise the episodic bursts of high levels of benzene emissions associated with coke ovens and gas processing plant operations, the release of fumes during the night and the impact of prevailing winds.

Return to top of page.....Return to Record of the Workers Inquiry

Title: Nev. Boy Dies of ***Cancer***; 13 Kids Ill
Author(s): N.A.
Source: Associated Press Online, 06/05/2001
AN: CX2001156U4859

Nev. Boy Dies of Cancer; 13 Kids Ill

ORANGE, Calif., Jun 05, 2001 (AP Online via COMTEX) -- Richard Jernee cradled his son's head in his hands, whispering in his ear: "I love you. Everybody loves you."

He said it over and over after doctors stopped the machine that was breathing for 10-year-old Adam Jernee. He said it until Adam died.

Adam became the first victim to die in a mysterious childhood-cancer cluster in Nevada.

Fourteen children have been diagnosed with cancer - all but one with acute lymphocytic leukemia - since 1997 in Churchill County, with 25,000 residents. Health officials have said acute lymphocytic leukemia normally occurs in about three out of every 100,000 children.

The cases are centered in and around Fallon, a Navy and farming community of 8,300 about 60 miles east of Reno.

"The focus now should be on these other children. It should be on what's causing it. That should be Adam's legacy. Not this. Not death," Adam's father said Monday, a day after the boy died at a Southern California hospital.

State and federal health officials have investigated a variety of conceivable causes in recent months, including the possibility that the cluster is simply a chance occurrence. They stepped up their investigation after Jernee took his son's story public several months ago.

The state has mapped the homes of the leukemia victims but found no clues. Investigators have begun inspecting the pipeline carrying fuel through the city to the Fallon Naval Air Station. Base officials have denied any link between jet fuel and the leukemia cases.

Some families have turned their attention to the water, where arsenic levels are higher than the federal standard. The city has been ordered to clean it up. Arsenic is a naturally occurring chemical that in high concentrations is poisonous. But it has never been linked to leukemia.

Still others believe government testing of nuclear weapons near Fallon in the 1950s may play a role. Radiation is a risk factor for leukemia, but tests for radioactive substances in the area proved negative.

"There's something there. There's something they're missing," Jernee said.

In recent days, Nevada's governor and members of the Legislature have pledged continued support to find the source of the cancer cluster.

When Jernee moved to Fallon in 1999, he said, it seemed like a good place to raise a family - little crime, good schools. As a newly divorced father, he spent time with his son exploring parks, riding bikes and cooking.

"I look back at it now and it was the happiest time in my life, in our lives," said Jernee, 33.

But by early 2000, Adam was fighting flu-like symptoms and coughing a lot. He

began to have problems breathing. Jernee took his son to the hospital several times before someone told him it might be a little more serious. Then came the telephone call: A fist-size tumor in the lung.

The survival rate of this type of childhood leukemia is 80 percent. And at first, chemotherapy reduced the tumor.

It was around then that Jernee ran into the mother of another victim and learned of a cancer cluster in Fallon. He attended a support meeting and began to talk to doctors.

But then Adam's cancer started to grow again. In the months that followed, Adam underwent another course of chemotherapy, a bone marrow transplant and radiation.

As his son's prognosis worsened, Jernee moved Adam to Southern California to be closer to his mother. In April, Adam underwent a second bone marrow transplant, a last effort to save the boy. Weeks later he slipped into a coma and then died.

"Even in the end, I hoped for a miracle," Jernee said. "I love Adam so much I didn't want him to suffer. But I didn't want to let him go either."

Jernee, who quit his job as a construction worker and has used up his savings to be near Adam, plans to return to Fallon this week to attend his son's memorial service and to pressure officials for more action.

"I'm going to do this for Adam. I can't do anything else until I find out why my son isn't by my side," Jernee said. "He'd want that, you know. He'd want to know why this happened to him."

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APO Priority=r
APO Category=1500

KEYWORD: ORANGE, Calif.
SUBJECT CODE: 1500

Source: Associated Press Online.
Item Number: CX2001156U4859

RENO GAZETTE-JOURNAL

Researcher trying to link jet fuel with cancer clusters

Frank X. Mullen Jr.
RENO GAZETTE-JOURNAL
1/28/2002 10:39 pm

An Arizona researcher said he plans to investigate whether the Fallon childhood leukemia cluster can be tied to four other possible cancer outbreaks near military bases in Arizona and California.

Mark Witten, a research professor in the Department of Pediatrics at the University of Arizona College of Medicine, is a national expert on JP-8 jet fuel. The fuel, in use at Fallon Naval Air Station since 1993 and used at military bases in Arizona and California, is among the suspected environmental causes of the Fallon cancer cluster of 15 children, two of whom have died.

"Do I think jet fuel is involved somehow? Yes, I do, but I don't have scientific proof," Witten said. "There is a huge number of environmental factors in Fallon, including jet fuel, a nearby bomb test in the 1960s, naturally occurring uranium in the water, arsenic in the water, and other factors.

"It could be everything or nothing. The only way we will know is to do the research."

Navy officials and the owners of the jet fuel pipeline that runs through Fallon have said there's no evidence jet fuel is connected to the leukemia cases. Tests of wells in the area last year by the U.S. Geologic Survey didn't detect fuel products in the drinking water.

The Fallon cancer cases began surfacing in 1997 and the 15th case was diagnosed in December. State health officials said the expected rate of childhood leukemia in the Fallon area should be about one every five years. Health investigators speculate that some environmental change occurred in Fallon in the early or mid-1990s to account for the unexpected surge in leukemia cases.

The federal Centers for Disease Control and Prevention and the federal Agency for Toxic Substances and Disease Registry have been doing human and environmental testing in Fallon since August. But investigators acknowledge the CDC's unprecedented probe may not ever connect the epidemic with an environmental cause.

State health officials and the CDC are looking only at Fallon and not other areas where there may be cancer clusters.

Witten, who is assembling a team of experts and applying for funding, said documenting similarities between Fallon and other cancer cluster sites may help provide an answer to the mystery.

He plans to examine jet fuel and other environmental factors in Fallon; Sierra Vista, Ariz.; Tucson, Ariz.; and two possible cancer outbreaks in California. All the sites are near military bases and all have jet fuel pipelines and frequent military jet flights near the homes of the patients. All the bases use JP-8 fuel.

In Sierra Vista, state officials confirmed six childhood leukemia cases. They said that number falls just one short of the outbreak being termed a cancer cluster.

However, Annastacia Warneke, 7, who moved from Sierra Vista to Fallon, was diagnosed with leukemia two weeks later and is counted as a Nevada case and not an Arizona case. That's because state health officials count cases where they were diagnosed, not where the disease symptoms first were noticed.

Matthew Warneke, Annastacia's father, said it defies common sense that his daughter isn't considered part of the Sierra Vista cases. He said she started showing symptoms of the disease — such as high fever and bone pain — while still in Arizona. He said Arizona officials are relying on the technicality of residence to exclude his daughter from the Sierra Vista cases.

"I think (Witten's investigation) is a great idea," said Warneke, whose daughter is in remission from the disease and doing well. "I've been saying all along that they should compare the two clusters. That's the only way they will find answers."

Witten said he also considers Annastacia Warneke part of the Arizona cases and the Sierra Vista outbreak as a cluster worth investigating. The community is near Fort Huachuca Army Base and he said four of the six leukemia patients' homes line up within a half-mile of the base's runway.

He said leukemia cases have also been reported in Tucson, near the Monthan Air Force Base, and at two sites in California which are also near military airfields.

"I need to visit those sites and see what the real numbers are and tour these areas and meet the people there," Witten said. "All I know is what we've seen so far is weird."

He said Karen Montgomery, who conducts genetic research at the University of New Mexico in Albuquerque, N.M., and David Harris, professor of immunology from the University of Arizona College of Medicine want to help in the investigation. Witten said the investigation team should also include experts in a variety of fields, including epidemiology and oncology.

Although Witten has met with lawyers for some Fallon families, he said he isn't interested in taking money from them or using the case to make money for others.

"I've got plenty to do already, but I am a professor in a Department of Pediatrics and I should be worried about children's health," he said. "Right now we are sure that kids in two Western sites are coming down with leukemia at an alarming rate and we need to do the best science we can and incorporate modern gene technology to try and figure this out."

Witten said his plan is in the fact-finding stage and it will take some time to get grants and permissions to do studies. He said the studies will look at jet fuel and other possible environmental factors.

"I'll give it a try," he said. "I've thought long and hard about getting involved in this and I feel a moral obligation I don't like to see kids get sick and die. Let's try and find out what's going on."

FAMILIES AGAINST CANCER & TOXICS

Stop cancer before it starts

SEPTEMBER 2, 2001

ARIZONA PROBING CHILDREN'S LEUKEMIA

The Arizona Daily Star - Sunday, September 2, 2001
Author: Carla McClain

Town's rate is twice state's; disease's cause is a mystery

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A high rate of childhood leukemia cases in Sierra Vista has triggered a rare state investigation.

Although the exact cause of leukemia is unknown, the disease has been linked to possible chemical and environmental toxins or infectious agents.

If such factors are found to exist in Sierra Vista, parents should be warned, say University of Arizona doctors who are treating these children.

"Any parent who has a child with leukemia wants to know what caused this, what could I have done to protect my child, and the parents in Sierra Vista are no different," said Dr. John Hutter, pediatric oncologist at University Medical Center.

"The problem is, we don't fully understand all the factors that cause leukemia - there is no 'aha, that did it.'

"But if you have a cluster of cases - and it looks like we may have one in Sierra Vista - we have to investigate it as best we can to see if there is some exposure that connects these children, and make our best effort to find out what it is."

The death of a 9-month-old Sierra Vista baby at UMC in June brought the number of leukemia-stricken children from that small Southern Arizona military town to a total of seven in the past five years, according to UMC and state health department records.

That puts the rate of acute childhood leukemia - a cancer of the blood and bone marrow system - at twice what would be expected, according to a preliminary study of the problem by the medical director of the Arizona Cancer Registry.

Nationally, acute leukemia strikes slightly over three per 100,000 children per year, with the disease occurring in four per 100,000 in Arizona.

But in Sierra Vista, the rate is now running at nearly eight cases per 100,000 children, according to state calculations.

"The issue now is what to do about it - is there something useful we can find out for these families," said Dr. Tim Flood, medical director of the Arizona Cancer Registry, who has investigated other cancer clusters in Arizona, most notably the 1980s childhood leukemia outbreak in Maryvale, a west-central suburb of Phoenix.

"But I have investigated so many of these and not really gotten anywhere, in all honesty. So I'd like to take some kind of different approach with this one. We want to get to Sierra Vista and talk to the families and find out what their concerns are. Do they have specific concerns about the environment, about pollutants there? What about the water quality?

"We know benzene can cause leukemia - is benzene in the area? These are the kinds of questions we have to ask, to get started."

Flood has asked for a mid-September meeting with pediatric oncologists and researchers at the UA's Steele Memorial Children's Research Center to plan the investigation.

After that, other state and county agencies may be called in to test soil, water and air, and

SECTIONS

» MAIN PAGE
» FACT SHEET INDEX
» UPDATES INDEX
» CLUSTERS
» LINKS
» DONATE
» TAKE ACTION
» BOOKS AND MOVIES
» OUR KIDS
» MISSION
» CONTACT

to analyze pesticide and chemical use in the region, along with investigators from the federal Centers for Disease Control and Prevention in Atlanta, he said.

Flood admitted he was at first reluctant to probe the Sierra Vista situation, because the case numbers are small. He also noted that cancer cluster investigations are expensive, can take years and often produce inconclusive results.

But controversy erupted when Flood eliminated one of the stricken children from the list of Sierra Vista-based leukemia cases, because she was diagnosed with the disease two weeks after she moved with her family from Sierra Vista to Nevada. Without that one case, the Sierra Vista rate is only "marginally elevated," Flood concluded in his preliminary analysis a month ago.

"The rules of how cancer registry counts are done are very clear - you only count the cases that are living there at the time of diagnosis," he said.

"Following that rule, this was a borderline situation. It is true that including that case pushes the rate to a significant elevation - a rate that signals a potential cancer cluster."

The decision not to count the case is "ridiculous," said UA pediatric research professor Mark Witten, one of those alarmed by the steady stream of Sierra Vista childhood leukemia cases.

"That child did not suddenly become sick during those two weeks in Nevada - she very clearly developed her leukemia in Sierra Vista, where she had lived for several years, and where she first experienced symptoms," said Witten.

"To not include her as part of the problem in Sierra Vista is absolutely, totally unacceptable. It defies common sense and logic."

The child's father, Matthew Warneke, confirmed that his daughter Annastacia displayed the first signs of her leukemia - bruising, anemia, fever - two months before she left Sierra Vista, last summer.

"They need to start an investigation down there. Otherwise, they are going to have a lot more sick children and they'll never know why. When we lived there, we knew several families with children with leukemia, and everyone was wondering what was going on," said Warneke, who said he called Flood months ago with his concerns.

"If an investigation is actually getting under way, I'm very pleased to hear it."

UA physicians are notifying all affected Sierra Vista families of the state probe and declined to identify any of the patients until that process is completed. State health officials have not pinpointed the exact locations of the leukemia cases within Sierra Vista, Flood said.

However, Witten said at least three of the leukemia children live in homes located in line with one of the aircraft runways off the Fort Huachuca Army base adjacent to Sierra Vista. For that reason, he suspects that exposure to noxious chemicals in jet fuel - which include benzene and kerosene - could be a factor.

"They have got to test soil samples, water samples, water wells, possibly even ambient air levels, to see if these chemicals are elevated where these people live," said Witten. He has studied the effects of jet fuel on animals and humans for 10 years and notes that damage to human tissue and organs begins at known levels of jet fuel exposure.

Witten said two other leukemia clusters under investigation - one in the San Diego area and the other in the small town of Fallon, Nev. - are near military bases with high-powered jet activity. He noted that Fallon - with more than 15 childhood leukemia cases in two years in a town much smaller than Sierra Vista - is the home of the U.S. Navy's "Top Gun" jet fighter training facility.

"I don't know if jet fuel is playing a role in these clusters or not, but epidemiologic studies have shown that the children of families that work in the hydrocarbon industries - auto mechanics, with petroleum products - have higher leukemia rates," he said.

"I would not be surprised to see a leukemia cluster within a mile radius of every major airport in the U.S., and I think we are just beginning to discover some of these. The main point is, this has to be investigated. The location of these clusters is forcing the question."

Concerns about the possible toxic effects of the U.S. military's new jet fuel formula triggered a recent Department of Defense study of jet fuel tank workers at six Air Force bases - including Davis-Monthan in Tucson - who handle the substance daily.

Conducted by the Air Force Institute for Environmental Safety and Occupational Health Risk Analysis facility in Texas, the two-year study's preliminary results show "no negative health effects from acute exposures" to jet fuel, said Betty Anne Mauger, spokeswoman for the Air Force surgeon general.

"We found no increased incidence of disease to these workers," Mauger said.

But Witten said the short-term nature of the study made any conclusions about long-term effects impossible, limiting the value of the findings.

"I smell a whitewash here," he said.

But jet fuel is only one of the suspects in the various childhood leukemia clusters being probed around the country. In Fallon, for example, residents point to arsenic levels in their water at 10 times the federal safety standard.

Releases of benzene and other toxic chemicals by maquiladoras in Mexico have been blamed for high rates of childhood leukemia and birth defects across the border in Brownsville, Texas.

And families involved in a cluster in Woburn, Mass., discovered in 1996, have raised concerns about high levels of the suspected carcinogen trichloroethylene - TCE - found in their water.

TCE-contaminated ground water was blamed for abnormal rates of several types of cancers on Tucson's South Side, in the wake of years of TCE dumping linked to nearby Hughes Aircraft, now Raytheon. And it was present for decades in the ground water in Maryvale, site of Arizona's largest childhood leukemia cluster .

In Sierra Vista, a myriad of factors - including the city's practice of pesticide spraying in residential areas - could play a role in the high leukemia rates, said Michael Gregory, director of Arizona Toxics Information.

Although there is no heavy industry in the Sierra Vista area, tanks of agricultural and other chemicals are likely buried, as they are in many areas of the West, and could be leaking toxins into the ground water, he said.

"The water in Sierra Vista is provided by many small water companies, and they are self-reporting and less likely to be as rigorously monitored as the big municipal water systems.

"You have to ask if anyone really knows what's in that water."

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Be on lookout for these symptoms

Childhood acute leukemia rates peak by age 4, but the disease can strike up to the early teens.

Although disease rates have been steadily rising in this country during the past 20 years, cure rates have risen even more dramatically - from only 1 percent in the 1960s to better than 75 percent today.

Parents are warned to watch for these symptoms of acute leukemia, which can be mistaken for other, less serious conditions:

Fatigue.

Persistent high fever.

Shortness of breath when active.

Pale skin from anemia.

Unexplained bruises.

Bone or joint pain.

Prolonged bleeding from minor cuts.

Sometimes headaches or vomiting.

Contact Carla McClain at 806-7754 or at cmcclain@azstarnet.com.

Title: Researchers still can't explain brain ***cancer cluster*** at Amoco center
Author(s): By Sallie L. Gaines and Ronald Kotulak
Source: Chicago Tribune, 08/05/1999
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Researchers still can't explain brain cancer cluster at Amoco center

Chicago Tribune

By Sallie L. Gaines and Ronald Kotulak

After three years, millions of dollars and countless manhours, frustrated medical researchers conceded Thursday they still are at a loss to explain a cluster of deadly brain cancers at BP Amoco Corp.'s Naperville, Ill., research center.

Researchers from University of Alabama-Birmingham and Johns Hopkins University concluded that six cases of the cancer, called glioma, are more likely than not to be workplace-related based on stark similarities of the victims.

All six were long-term white male employees who worked in Building 503, most on the third floor and on similar projects, during the same years in the late 1970s and early 1980s.

But 13 other tumors, all benign, show no pattern that suggests a link to the job, the researchers added - a conclusion sure to spark anger and protests from those patients and their attorneys.

Although the findings are disappointing and leave many questions unanswered, the study itself is considered unprecedented and may spur other companies to investigate other workplaces. On-the-job exposures are believed to account for up to 10 percent of all cancers.

The tumors at the BP Amoco center, particularly the rare and puzzling gliomas, have generated more than a dozen lawsuits but little noticeable fear at the Naperville campus, where a briefing on Thursday's report drew only about 175 of 800 employees.

While researchers couldn't identify what may have caused the gliomas, they did uncover two tantalizing clues, said Michael S. Wells, manager of health, safety and environment at the site.

A chemical called n-hexane, which is used to make plastics, and a process involving ionizing radiation, used to track individual compounds in chemical reactions, were used more by the six glioma victims than their counterparts at the center.

While n-hexane and ionizing radiation can be linked to specific health risks under certain circumstances, Wells said the researchers are almost certain neither agent is the culprit in the glioma cases. N-hexane hasn't been linked to cancer, and the BP Amoco researchers were exposed to far less ionizing radiation than is considered dangerous, he said.

``Those agents are probably not the agents that caused the brain cancers," Wells said. ``There was possibly something underlying the projects."

The next step will be to look for more clues in those projects. BP Amoco will ask third-party researchers who are expert in n-hexane and ionizing radiation to review and confirm the study's conclusions and make suggestions about further steps.

But Jim D. Lowry, head of BP Amoco's task force on the glioma cluster, cautioned that further study likely will yield little valuable information because six patients is too small a sample.

``They may not be able to go much further with this data - there isn't a lot of it."

Other than that, BP Amoco plans to monitor its work force, fund further research and hope that publishing of results so far will spur other companies and researchers to look for similar patterns. That could generate a larger database of glioma cases thatwould allow researchers to see patterns more clearly.

``We must rely on the outside world for some help," Lowry said.

The study has cost BP Amoco ``considerably" more than $1 million, Lowry and Wells said, though they wouldn't be specific. They also noted that several company employees are spending virtually all their time on the cancer-cluster puzzle.

The study was launched in 1996 after a fourth case of deadly glioma was discovered among current or former employees of Building 503 at the Naperville center of what was then Amoco Corp. Although the incidence of brain cancer has increased to 7.2 cases per 100,000 men in 1996 from only 5.9 cases per 100,000 in 1973, it remains a relatively rare - and little understood - disease.

The Chicago-based company was acquired by British Petroleum PLC last Dec. 31, and it has kept Amoco's commitment to try to find a cause of the cancers.

But even at the beginning of their detective work, Wells and Lowry cautioned that the likelihood of pinpointing a single specific cause was a long shot.

Nevertheless, Thursday's announcement was bitter.

``It's frustrating, obviously, to spend three years studying something and not have a definitive answer to give," Lowry said.

But he refused to characterize the study results as failure.

``We're also a little hopeful," he said. ``What was done here has never been done before."

Specifically, the Alabama-Johns Hopkins study covered more ground than any similar effort ever had before, Lowry said. The study included all of the approximately 7,000 people who have worked at the Naperville campus since it opened in 1970 as well as the more than 6,700 chemicals that have been used there.

However, the final step - the case control study announced Thursday - looked only at the six gliomas and six benign tumors among employees in the three buildings that make up the 500 complex.

Each of those 12 were compared with approximately 10 other healthy employees at the same complex matched by sex, race and type of work. A total of 131 people were included in the study, most of them in the healthy control group.

The goal was to see whether there were any striking differences between the two groups; the only differences uncovered were the degrees of exposure to n-hexane and ionizing radiation.

Results of the study are unlikely to end speculation that other illness among current and former employees may be linked to the job. The majority of lawsuits filed against BP Amoco to date are on behalf of people with other illnesses, ranging from lung cancer to benign tumors.

Critics also have questioned the Alabama and Johns Hopkins researchers' decision to limit the study to tumors in the neck and head. Wells noted that early steps of the study did look at broader health questions and other cancers, but didn't find any unusual patterns.

Until recently, the official number of cases in the study was 20, including seven gliomas and 13 benign

tumors. But in the course of confirming diagnoses, researchers determined that one of the cases classified as a glioma really was another form of cancer, and it was dropped from the study.

Before the public announcement of the study's findings, lead researcher Dr. Elizabeth Delzell of University of Alabama reviewed them with employees at the Naperville campus.

About 175 of the 800 employees showed up, but asked few questions - and those were about technicalities of the study's design, not the results, several BP Amoco people said. One person who attended the meeting noted that because most employees at the research center have scientific backgrounds, they were not surprised by the results.

Nonemployees were not allowed into that briefing, and Delzell refused to talk to reporters. Wells said protocol forbids researchers from talking publicly about their work until it has been published and subject to peer review.

Delzell plans to publish her findings, but no date was given.

Meanwhile, the third floor of Building 503, remains closed.

Source: Chicago Tribune.
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The New York Times

Education

Study Cites Illness in Alumni Of Schools on Industrial Sites

By JACQUES STEINBERG
Published: March 19, 2001

While being treated for leukemia seven years ago, Kim Tolnar, a 1983 graduate of River Valley High School near Marion, Ohio, was contacted by another woman who had attended the same school in the late 1980's and was battling the same disease.

The two young women soon discovered nine other cases of leukemia among the more than 5,500 students who had attended the school since it opened in 1963. The number of cases in a population that size over that period would ordinarily be expected to be three, statisticians said.

Though district officials knew the school had been built on the site of an Army depot, not until the leukemia cases surfaced did they learn that part of the site had been an Army dump for solvents and automotive lubricants.

The story of River Valley and the arguments for and against closing it are in 1 of 15 case studies in a report to be released today by a coalition of parent and community activists known as the Child Proofing Our Communities Campaign. The report's authors said that serious health problems reported by graduates of schools built on old landfills and factory sites were increasing but that districts still relied on such sites for schools.

In describing the appeal of such locations, school districts cite the pressures of escalating enrollments and real estate prices, and they argue that there is little cause for concern unless a link between the chemicals on a site and a cluster of cancers can be confirmed. Districts also say that clusters of cancer cases can simply be statistical aberrations.

Dr. Philip J. Landrigan, the director of the Center for Children's Health and the Environment at Mount Sinai School of Medicine in New York, who was not involved in the study, suggested that districts should err on the side of children when chemicals were involved.

"I don't think anyone would disagree with the proposition that children should go to school in a safe place," Dr. Landrigan said. "The critical issue is where you set the threshold.

"The way in which regulation works in most circumstances is that chemicals are considered innocent until proven guilty," he added. "But when there's a preponderance of evidence, I think it's probably more reasonable to act."

At River Valley, in a rural community of Marion County about 45 miles north of Columbus, about half of the school's 78 acres have been fenced off, including several ball fields where chemicals known or suspected to cause cancer were detected.

State and district officials contend that the school's occupants face no risks, so River Valley High will remain on the site until at least 2003, when a new school is to be built. But people who believe they are victims of the location are not pleased.

"It infuriates me that there are kids right now going to school there," said Ms. Tolnar, 36, whose cancer is in remission. "There are parents who know about what happened to us, and they still don't get it."

Among the other cases examined in the report was that of a high school in Elmira, N.Y., where 22 cases of cancer, including testicular cancer, were confirmed among 7,500 people who attended in the last two decades. The land on which the school was built had been used for industrial purposes as far back as the Civil War. State officials have declared the school safe, but parents dispute those findings and want it closed.

Trying to rebut the arguments of school districts that consider former industrial sites cost-effective, the report's authors recount the travails of the Los Angeles school system. As early as 1993, state officials warned the school district about the dangers of building a high school on an abandoned oil field, but their concerns went unheeded. Last year, after spending more than $125 million on the project, the district scrapped it, largely because methane was seeping out of the soil.

"You could look at what happened at Love Canal and say, 'We didn't know there was a risk,' " said Lois Gibbs, whose family was among hundreds of people who fled that upstate New York community two decades ago after learning that it had been built on a toxic dump.

Ms. Gibbs, the executive director of the Center for Health, Environment and Justice, a nonprofit organization in Washington, helped organize the study to be released today.

That such cases can be complicated is underscored by the continuing fight over River Valley High.

Tests have revealed elevated levels of benzo(a)pyrene, a carcinogen similar to the tar in cigarettes, and tricholorethylene, a widely used solvent that might be carcinogenic, in the soil around the school. But state health and environmental officials have said there is no way for students to ingest or inhale those chemicals, particularly with the ball fields closed as a precaution.

"Contaminated doesn't mean it's dangerous," said Thomas G. Shade, the superintendent of the River Valley school district, who supports the school's continued operation. "It just means it's contaminated."

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Section: News Report

Breast Cancer

CLUSTERING MAY BE LINKED TO MILITARY TESTS

A cancer specialist told a National Academy of Sciences panel that he has found a cluster of breast cancer cases in an area where the Army conducted Cold War chemical experiments during the 1960s.

Six women diagnosed with breast cancer before age 30 had lived as toddlers in a one-mile-square section where, according to Army reports, the Army dropped its highest concentrations of zinc cadmium sulfide on Fort Wayne, Dr. Joseph Gibbons said.

"We had wondered for some period of time what could have caused this in so many young women," the Fort Wayne, Indiana, oncologist said. "It's an unusual cluster. Whether we could see it by chance alone we don't know."

Gibbons was among 200 people who attended the daylong hearing on July 31, 1995.

The Army used airplanes to drop about 3,500 pounds of zinc cadmium sulfide, a carcinogen, on Fort Wayne during 70 trials from 1964 to 1966. More than 20 areas nationwide were included in the tests over 20 years beginning in 1949.

The tests were part of the Army's biological warfare research program, designed to tell Army personnel how chemicals would fall onto a city. The Army has told Sen. Dan Coats, R-Indiana, that Fort Wayne residents have nothing to fear from the tests.

However, the National Academy of Sciences is conducting a $1 million independent analysis of the possible health risks associated with the tests.

Norma Jean Steiss told the subcommittee that she granted permission to men from a Connecticut-based organization called Travelers Research Center to place a canister in her yard as part of what they called meteorological research.

She grew angry when she learned in 1995 the canister was part of a Cold War experiment. She said she has malignant skin cancer and has had breathing problems and back pain.

"I'm a human being, not a guinea pig," she said.

Rogene Henderson leads the academy subcommittee that is assessing the health risks from exposure to the chemical.

She told the audience that the panel would not conduct new research such as soil samples or epidemiological studies but would rely on data already available. The subcommittee will recommend those studies if it believes they are necessary.

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By Sandra W. Key, News Editor, with Michelle Marble

Source: Cancer Biotechnology Weekly, 8/14/95 & 8/21/95, p4, 2/3p.
Item Number: 9509115015
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Elmirans to testify about cancer

Congressional hearing takes a look at clusters throughout New York state.

By MARGARET COSTELLO
Star-Gazette
mcostello@stargazette.com

An Elmira city councilman and a parent of a Southside High School student who has cancer are among those who will testify today during a congressional hearing on Long Island about cancer clusters in New York state.

U.S. Sen. Hillary Rodham Clinton invited some local people, including Councilman Jim Hare, D-6th, and Timothy Tobin of Elmira, the father of junior Michael Tobin, to speak about their experiences regarding environmental contamination at Southside, which was built on a former industrial site.

The state Health Department is investigating a cancer cluster in Elmira - an unusually high number of testicular cancer cases among Southside alumni since 1997.

The state, as well as several independent environmental firms, has ruled that the low levels of contamination on the school grounds do not pose a health risk to students and staff.

However, some families of those inflicted with the disease don't agree with those findings and believe that the former industrial site has left a legacy of environmental problems on the school grounds and in neighborhoods downstream from the site.

Clinton, D-New York, believes that while there have been advances in pinpointing the genetic causes of cancer, the "new frontier" of cancer research concerns the environment.

"From the high rates of cancer at a high school in Elmira to the alarmingly high breast cancer rates on Long Island, communities in

New York and around the country want to know what's making them sick - it's time for us to step up our efforts to find the answers," Clinton said last week.

"The link between our environment and our health is one of the big black holes of scientific research that we need to illuminate. Although many people believe that the environment plays some role in the incidence of cancer and other chronic diseases, we have yet to be fully determined what that role is," she said.

Clinton traveled with Sen. Harry Reid, D-Nevada, to Fallon, Nev., in April to examine a childhood leukemia cluster there. Now Reid and five Downstate state representatives will join Clinton at the Environment and Public Works Committee hearing at Adelphi University in Garden City beginning at 9 a.m.

Today's hearing will focus on breast cancer on Long Island but will also look at environmental links to disease in general, including the studies being conducted in Elmira.

The hearing will include testimony from survivors and community members dealing with chronic diseases and potential environmental threats, as well as leading scientists, medical experts and federal agency representatives who are studying these connections.

The Elmira City School District expects to send out medical surveys this fall to all Southside alumni since 1979 to include in the state's ongoing cancer surveillance initiative. So far, the state has confirmed 22 cancer cases among alumni since 1980 with the state cancer registry. That's approximately half the number expected statistically during that time period.

Using the cancer registry, the state discovered that 22 children younger than 19 in a three ZIP-code area were diagnosed with cancer from 1980 to 1998, including nine with leukemia. A total of 23 cases were expected statistically among children, including six leukemia cases.

State health officials are continuing to monitor cancer rates in Southside neighborhoods, although they do not believe they'll be able to pinpoint a specific cause.

On Long Island, some residents have suspected that pesticides, power lines and tainted groundwater have played a role in the region's above-average breast cancer rate.

Fran Kritchek says she knows what caused her breast cancer: the pesticides sprayed on Long Island's suburban lawns to keep them green. But scientific studies have in most cases failed to prove a direct

link between environmental factors and neighborhood breast cancer clusters.

Still, when it comes to breast cancer, Long Island is known as ground zero. That's in part because of a well-organized network of activists like the group One In Nine, which organizers said was named for the likelihood of a woman getting breast cancer.

Long Island's central role is also because of the political muscle of former Sen. Alfonse D'Amato, who made the concerns of his native region known in Washington.

It was D'Amato who helped get the money to start a full-scale study of the area by National Cancer Institute. The Long Island Breast Cancer Study Project is in the midst of several studies of possible environmental links.

One study is investigating the impact of electromagnetic fields, the current flowing from power lines. Another is examining a potential link to chemicals such as DDT or polychlorinated biphenyls, or PCBs. Findings from both studies are expected later this year or early next year.

Throughout New York state, 104.1 women out of 100,000 reported contracting breast cancer. In Suffolk and Nassau counties that figure was 118.2 and 115.6 respectively. In Rockland County the rate is 118.5 per 100,000, the Health Department said.

"The rates on Long Island are higher, but they are not enormously higher," said Dr. Robert Smith, director of cancer screening for the American Cancer Society.

Smith is chairman of the advisory committee overseeing New York's cancer mapping effort in which cancer incidences and possible risk factors are being sketched out in detailed maps. He said breast cancer rates are higher throughout the Northeast.

"It is notoriously difficult to link one environmental factor with a specific type of cancer," Smith said, noting that genetics and lifestyle are among the other factors also involved.

Tom Sinks, an epidemiologist with the Centers for Disease Control who studies cancer clusters, also sounded a cautionary note.

In the past, the study of cancer clusters has led to discovery of some specific carcinogens such as asbestos, he said.

"But it is premature just to jump to the conclusion that because the rate

is 10 to 20 percent higher that there is something in the environment doing that," Sinks said.

He said smaller studies in the early 1990s suggested PCBs may elevate the risk of breast cancer but larger follow-up studies have been inconclusive. He said more study is needed to find other causes of cancer.

Shannon McCaffrey of The Associated Press contributed to this report.

Southside News Index

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RESIDENTS NEAR THE WELDON SPRING CLEANUP SITE WONDER WHAT'S CAUSING A STRING OF INFANT DEATHS AND OTHER ILLNESSES RASH OF CASES TERRIFIES NEIGHBORS, BUT STUDIES USUALLY FIND NO LINKS

St. Louis Post - Dispatch; St. Louis, Mo.; Jan 7, 2001; Deborah L. Shelton Of The Post-Dispatch;

Sub Title: [FIVE STAR LIFT Edition]
Start Page: A.1
Subject Terms: Neighborhoods
Public health
Statistics
Environmental cleanup
Illnesses
Infant mortality
Contamination
Geographic Names: Weldon Spring Missouri

Abstract:

(Note: The THREE STAR ran items 3-6 as black and whites.) Color Photos by ANDREW CUTRARO /POST-DISPATCH (1) [Ann Bachmann] holds her son Dominic in their O'Fallon, Mo., home. Two years ago, Dominic's identical twin brother died 16 hours after being born with a partially developed brain and skull. Bachmann and her neighbors who have noticed health problems in their children think there might be a connection to the Weldon Spring cleanup site. "The red flag for me was all the babies we were burying," Bachmann said. (2) Holiday decorations adorn the grave of David Lael Bachmann in the graveyard at the Immaculate Conception Church of Dardenne in Dardenne Prairie. The 2,500-family congregation has witnessed the recent deaths of seven infants. (3) [Amy Craig], 32, of O'Fallon, Mo., gave birth to stillborn twin girls in June. Then she began to hear about the other stillbirths and deaths of infants in the area. "When you go through something like this and you hear about so many other people who have lost infants or have had health problems -- so many in one area -- it makes you think," Craig said. (4) Post-Dispatch Color Graphic/Chart - An abrupt jump in disease often reflects randomness Source: Missouri Department of Health statistics A true disease cluster represents a higher incidence of cases or deaths from the disease than would be expected to occur in a given time period or geographic area. Numbers will always vary from time to time, community to community. For example: The following (bar) chart examines the annual number of deaths from cancer between 1990 and 1997 in the 63108 ZIP code in the Central West End area of St. Louis. 1990: 87 1991: 64 1992: 82 1993: 65 1994: 52 1995: 57 1996: 62 1997: 49 8-YEAR AVERAGE: 64.75 At first glance, one might be suspicious of the higher number of cases in both 1990 and 1992, but experts say such spikes are a normal occurrence over time just as are the low incident rates in 1994 and 1997. (5) Post-Dispatch Color Graphic/Chart - Causes of cancer Source: Richard Doll and Richard Peto, 1981; Missouri Department of Health 2% - Pollution 4% - Occupational 7% - Sexual behavior 10% - Infections 12% - Other* 30% - Tobacco 35% - Diet * Includes unknown as well as hereditary and miscellaneous causes. (6) Post-Dispatch Color Map - Weldon Spring cleanup site Missouri state map showing location of St. Charles County. AREA OF DETAIL map showing the location of the Weldon Spring cleanup site near the southwest intersection of Highways 94 and 40/61.*

Full Text:

SEARCHING FOR CANCER CLUSTERS Reporter Deborah L. Shelton: E-mail: dshelton @post-dispatch.com Phone: 314-862-2181 {TYPE} CANCER CLUSTERS WELDON SPRING CLEANUP SITE

* RESIDENTS NEAR THE WELDON SPRING CLEANUP SITE wonder what's causing a string of infant deaths and other illnesses. But investigators have found no connection among the cases -- or to the former ordnance works.

Amy Craig gave birth to stillborn twin girls in June. Then she began to hear about the other stillborns and dead infants of fellow congregants at the Immaculate Conception Church of Dardenne in St. Charles County. One newborn died the prior November, another in April, another in June.

And since Craig, 32, lost her twins this summer, the deaths have continued. A sixth baby died in July, a seventh in October.

"When you go through something like this and you hear about so many other people who have lost infants or have had health problems - - so many in one area -- it makes you think," said Craig, of O'Fallon, Mo.

Craig and some other O'Fallon residents believe their neighborhoods are witnessing a rash of infant deaths and cancer cases, including childhood leukemia. They want to know why. And they look just a few miles to the south for their suspected cause: the $800 million federal cleanup of the old explosives and uranium complex at the Weldon Spring Remedial Site Action Project.

But public health officials don't believe there's any danger or connection to Weldon Spring. They also have not found any link between the seven deaths.

The studies conducted by the Missouri Department of Health and the federal Agency for Toxic Substances and Disease Registry also have not uncovered higher-than-expected rates of disease in the community.

Those findings aren't surprising -- at least to the investigators.

Commonly held beliefs among the public that environmental factors are a major cause of diseases just aren't true, public health officials say.

Cluster investigations almost never find actual excess cancer. A cluster represents a higher incidence of cases or deaths from a disease than would be expected to occur in a given time period or geographic area.

Of the 184 cancer-cluster investigations conducted by the Missouri Health Department since 1985, only one found evidence of a higher rate of cancer than would be expected to occur. And even that case had mixed findings.

The fact that public health officials have been unable to find a link between the Weldon Spring site and the cancer and infant deaths - - or even to find a cluster of cases -- has not satisfied some environmental activists and St. Charles County residents.

"When government agencies do a study they almost always say there is no link between disease and a suspected environmental contaminant," said activist Kay Drey of University City. "They might not have any proof, but citizens who are living through these horrors know from their own experiences and those of their neighbors that something is wrong."

Calls to public health agencies about suspected clusters from groups and individuals have been on the rise nationally.

Denise Jordan-Izaguirre, senior regional administrator for the Agency for Toxic Substances and Disease Registry in Kansas City, said the rise in requests for investigations is due to "growing concern about environmental hazards and the impact they can have." Those suspected hazards, she said, are often linked with real or perceived increases in cancer incidence and deaths.

Based on inquiries from residents about possible cancer surges, Missouri health officials are deciding whether to begin new studies in five communities across the state. Health officials declined last week to provide details on those cases because a determination has yet to be made about whether to investigate further.

The Illinois Department of Public Health has conducted similar studies in recent years in the Metro East cities of East St. Louis, Belleville, Roxana, Wood River and O'Fallon. None uncovered excessive cancer rates.

Hard to prove

Cancer is the second-leading cause of death in Missouri, claiming about 13,000 lives each year. Heart disease is the No. 1 killer.

About 28,000 new cases of cancer are diagnosed annually. About one in three Missourians will develop cancer in their lifetimes. Experts say unhealthy behaviors, such as smoking, poor eating, lack of exercise and excessive exposure to the sun, are largely to blame. And because the population is aging, there are more cancer cases to see and more opportunities to detect patterns.

That's not to say that clusters don't exist. Several well- documented cases of cancer clusters have been linked to environmental causes:

* The dangers of inhaling asbestos became known only after cluster studies linked exposure to the material to a type of lung cancer.

* In the 1970s, studies revealed that a sharp increase in a rare cancer of the vagina in young women was due to exposure in the womb to diethlystilbestrol, a medication widely prescribed to pregnant women to prevent miscarriages.

* A real-life cluster of childhood leukemia cases in Woburn, Mass., was recently depicted in the film "A Civil Action."

But clusters are notoriously difficult to prove.

"The information we have is fragmented; it's not easy to put them together and look at correlations," said Dr. Tiefu Shen, division chief of epidemiologic studies for the Illinois Department of Public Health. For every correlation, researchers can always find another community where the same contaminant exists without the same rate of cancer, he said.

"How do you explain that?" he asked. "There are a lot of questions we simply can't answer."

Missouri medical epidemiologist Dr. Eduardo J. Simoes compares the investigation process to looking for a needle in a haystack. "Cancer cluster investigations test the limits of science," he said.

Several factors typically complicate such studies:

* The number of cases involved is usually small, which compounds the difficulty of determining their significance.

* Mobility makes it difficult to determine where a person might have been exposed to a cancer-causing agent.

* People can be exposed to multiple carcinogens over a lifetime.

* Cancer develops slowly, usually appearing five to 40 years after exposure to a known carcinogen.

And there's a matter of simple statistics. No disease spreads evenly across a population.

"For an average to occur, you have to have some areas that are high and some areas that are low," said Stanley R. Cowan, comprehensive cancer coordinator for the Missouri Health Department's bureau of cancer control.

Doubts and suspicions

Some residents living near the Weldon Spring site are not reassured.

Two years ago, one of Ann Bachmann's identical twin sons died 16 hours after being born with a partially developed brain and skull.

Over the years, her five children have struggled with numerous health problems. Friends and neighbors have shared similar experiences of fighting chronic illness.

"The red flag for me was all the babies we were burying," said Bachmann, who does pastoral counseling at Immaculate Conception Church of Dardenne, the 2,500-family congregation that witnessed the recent deaths of the Craig twins and five other infants.

Craig said she hadn't given Weldon Spring a second thought until this summer. Now, she and her husband, Tim, 38, parents of Allison, 5, and Adam, 2, are considering moving.

"I don't want to raise my family in an area that might cause them health problems," said Tim Craig, a computer-programming consultant.

U.S. Department of Energy officials say the Weldon Spring site presents no health risks to the public.

Contaminated ground water at the site, which is regularly monitored, doesn't connect to public water supplies or to private wells, said Tom Pauling, an environmental engineer overseeing ground water.

A huge dome of rock, soil and synthetic material built over collected solid waste can keep the contaminants safely in place for at least 1,000 years, said acting project manager Glen Newtown.

Doubtful of a cluster in the area, public health officials point to the wide variety of health problems being reported.

Although cancer is commonly viewed as one disease, it's actually a term that covers more than 100 different types, each with its own causes, course of progression and treatments.

"Having too many different types of cancer makes the case against a single environmental agent as causal in that community," said state medical epidemiologist Simoes.

Are cluster investigations worth doing, given the many questions and doubts? Some epidemiologists say they're largely a waste of time.

Dr. Kenneth Rothman of the Boston University School of Public Health, a longtime critic of the studies, said such investigations are useful only when studying rare or previously unknown cancers, like the vaginal cancer discovered in young women.

"But they don't yield useful information if you're looking at leukemia or breast cancer or some of the other common cancers," he said.

Other epidemiologists hope cluster studies will one day reveal new routes of exposure to cancer-causing agents and help to improve researchers' understanding of disease and the reasons for the emergence of excess cases in certain areas.

The studies also have helped to uncover other health problems and can result in improved public education efforts, said Jordan- Izaguirre. Lung cancer clusters tied to high smoking rates in a community, for example, have led to the creation of programs aimed at lowering smoking.

"Often an investigation doesn't establish a cluster," Simoes said, "but it can still help clean up the

environment or lead to behavioral changes that can result in fewer cancer cases."

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To report a suspected illness cluster, you can contact:

* Stan Cowan, Missouri Department of Health, 573-522-2841.

* Division of Epidemiologic Studies, Illinois Department of Health, 217-785-1873.

* Denise Jordan-Izaguirre, Agency for Toxic Substances and Disease Registry, 916-551-1310.

For a free booklet on cancer in Missouri, order:

* "The Good Race: Cancer Prevention and Control in Missouri," Missouri Department of Health, Bureau of Cancer Control, P.O. Box 570, Jefferson City, Mo., 65102-0570.

Or phone toll-free: 1-800-316-0935.

E-mail: cowans@mail.health.state.mo.us

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Infant deaths in St. Charles County

The deaths within a year of seven infants in a congregation of 2,500 families has spurred fears in O'Fallon, Mo., that an environmental hazard is responsible. However, state health officials say the wide range of h ealth problems reported there suggest just the opposite: that there is no single cause of death. Additionally, health studies have not found any clustering of disease in the area. Below is a list of the infants and the circumstances of their deaths.

* A five-day-old boy died in November 1999 after his lungs failed to fully develop.

* A boy born prematurely in April 2000 with underdeveloped lungs died three hours after birth.

* A set of twin girls were stillborn in June at 22 weeks from a condition that prevented them from getting adequate nutrients before birth.

* A girl died in June, 23 days after being born with severe disabilities.

* A girl diagnosed with Down syndrome in the womb was stillborn in July.

* A girl born with a twin in October died shortly after a premature birth, weighing less than one pound. The baby's parents had just relocated from Texas the previous month.

[Illustration]

PHOTO, GRAPHIC, MAP; Caption: (* Note: The THREE STAR ran items 3-6 as black and whites.) Color Photos by ANDREW CUTRARO /POST-DISPATCH (1) Ann Bachmann holds her son Dominic in their O'Fallon, Mo., home. Two years ago, Dominic's identical twin brother died 16 hours after being born with a partially developed brain and skull. Bachmann and her neighbors who have noticed health problems in their children think there might be a connection to the Weldon Spring cleanup site. "The red flag for me was all the babies we were burying," Bachmann said. (2) Holiday decorations adorn the grave of David Lael Bachmann in the graveyard at the Immaculate Conception Church of Dardenne in Dardenne Prairie. The 2,500-family congregation has witnessed the recent deaths of seven infants. (3) Amy Craig, 32, of O'Fallon, Mo., gave birth to stillborn twin girls in June. Then she began to hear about the other stillbirths and deaths of infants in the area. "When you go through something like this and you hear about so many other people who have lost infants or have had health problems -- so many in one area -- it makes you think," Craig said. (4) Post-Dispatch Color Graphic/Chart - An abrupt jump in disease often reflects randomness Source: Missouri Department of Health statistics A true disease cluster represents a higher incidence of cases or deaths from the disease than would be expected to occur in a given time period or geographic area. Numbers will always vary from time to time, community to community. For example: The following (bar) chart examines the annual number of deaths from cancer between 1990 and 1997 in the 63108 ZIP code in the Central West End area of St. Louis.

The New York Times

Critics Question Overdue Plan to Track Cancer and Pollution

New York Times; New York; Jan 18, 1999; Richard Perez-Pena;

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Pollution
Mapping
Legislation
Toxicity
Hazardous substances
Counties
Activists
Geographic Names: New York
Personal Names: **Pataki, George**

Abstract:

It was an audacious plan standing uneasily at the intersection of cancer science and cancer politics: to explore possible links between pollution and cancer by mapping every neighborhood in New York State, showing cancer cases and sources of water, ground or air contamination. Nothing like it had ever been attempted.

Nine months after the veto, the project has strayed far from what the Legislature intended. The (George E.) Pataki administration intends, at least at the start, to map cancers only on a county-by-county level, though that information is already public and researchers say it has little scientific value. Administration officials say they are not sure whether the first round of maps will include any information on contaminants, which legislators and cancer survivors say is the whole point of the project.

The cancer map was first proposed by cancer survivors on Long Island's eastern end, where breast cancer and other cancers are more prevalent than statewide or nationwide. Those advocates had charted suspected cancer clusters in their own villages, by ZIP code, by type of cancer and by proximity to hazardous-waste sites, an exercise they hoped to duplicate across New York.

Full Text:

It was an audacious plan standing uneasily at the intersection of cancer science and cancer politics: to explore possible links between pollution and cancer by mapping every neighborhood in New York State, showing cancer cases and sources of water, ground or air contamination. Nothing like it had ever been attempted.

Last year, the Legislature allocated $1 million for the effort, but Gov. George E. Pataki vetoed it. The Governor said the project could be accomplished with existing funds, and, mindful of the powerful cancer survivors' lobby, he promised that the State Health Department would proceed with the project. The veto, however, meant that it was no longer a legislative mandate; it was entirely in his administration's control.

Nine months after the veto, the project has strayed far from what the Legislature intended. The Pataki administration intends, at least at the start, to map cancers only on a county-by-county level, though that information is already public and researchers say it has little scientific value. Administration officials say they are not sure whether the first round of maps will include any information on contaminants, which legislators and cancer survivors say is the whole point of the project.

The Health Department says it will eventually create truly local maps, including environmental data, but it cannot say when.

Perhaps most disturbing to advocates of the project is that it has become clear that maps of any kind are years away, even though administration officials promised last year that preliminary maps would be published within months.

Cancer survivors' groups, particularly those on Long Island, and environmentalists keenly want to see the maps to validate long-held suspicions that there are higher-than-expected concentrations of similar cancers in one discrete area -- so-called cancer clusters -- that can be traced to landfills, factories or water wells.

But the scientific establishment has largely dismissed the notion that cancer clusters can be traceable to environmental causes. And corporations that own polluted sites, and some real estate interests, have quietly lobbied against the project, fearing the liability it could mean for them.

The administration contends that it must proceed cautiously to produce the best possible data, and some of its independent scientific advisers agree. It also asserts that if it publishes maps without great care and a heavy layer of interpretation, it risks alarming or confusing the public.

The administration's critics counter that the state already has the raw data to do a basic version of the maps in weeks or months and that more nuanced ones could come later. They say the public has a right to see where cancer "hot spots" coincide with pollution. Researchers would then know where to look for more finely honed data, the critics say, giving a head start to establishing environmental causes for a disease that kills 40,000 New Yorkers a year.

"What we're getting instead of a cancer map is an empty and misleading effort that does nothing to place the facts before the people of the state," said Assemblyman Richard L. Brodsky, chairman of the Environmental Conservation Committee. He was a prime sponsor of the mapping bill that the Governor vetoed and is one of more than a dozen Assembly members who wrote last week to the Health Department, expressing concern at the project's direction.

Zenia Mucha, Mr. Pataki's communications director, said: "The Department of Health has to do what they think is the best scientific study they can do. We're not going to allow political considerations or political pressure to dictate how to do a scientific study."

The cancer map was first proposed by cancer survivors on Long Island's eastern end, where breast cancer and other cancers are more prevalent than statewide or nationwide. Those advocates had charted suspected cancer clusters in their own villages, by ZIP code, by type of cancer and by proximity to hazardous-waste sites, an exercise they hoped to duplicate across New York.

Like these amateurs, private researchers and government agencies have occasionally done local cancer mapping where there was already suspicion of a cluster, but no one has ever attempted a detailed cancer map of a state.

There seems no doubt that some form of statewide maps could be produced in short order. The Health Department has a cancer registry, which collects the name, address and type of cancer for every New Yorker found to have the disease or determined by autopsy to have had it. The department uses the data to publish annual reports on cancer incidence.

The state also knows the locations of 2,000 toxic-waste sites, 400 industrial sites it says are responsible for 95 percent of toxic releases into the environment, every landfill and other pollution sources. "The cancer data already exist and the environmental factor data already exist," Mr. Brodsky, a Westchester Democrat, said. "What the Legislature intended was that the two be overlaid in the quickest responsible fashion."

Last spring, Dr. Barbara DeBuono, then the State Health Commissioner, wrote to cancer survivors'

groups, saying preliminary maps were just months away. But members of the department's advisory committee on the project, which met for the first time in December, say they were told that the first maps were probably two years away, a timetable that department officials privately confirmed.

The first maps, department officials say, will show cancer rates by county. The department already publishes annual reports with county-level data, so such maps would simply repackage the same information.

"That tabular data exist, but it is not easy for the lay person to read," said Kristine A. Smith, a department spokeswoman. "A graphic representation of information is much more understandable."

But members of the department's own advisory committee on the project question whether there is a point to county-level maps. "If the information is already published, I'm not sure why you'd publish it again in a different form," said Lorraine Pace of West Islip, N.Y., a committee member and breast cancer survivor. She is a cancer educator at University Hospital at Stony Brook and co-president of Breast Cancer Help, a survivors' group.

Scientists on the advisory committee say that even if county-level maps could supply new data, they would be of little use because cancer clusters would occur on a much smaller level, in villages, neighborhoods, even individual blocks.

State officials say that in rural areas, more detailed maps could violate patients' privacy, making it plain to neighbors, for instance, who in a particular ZIP code has a particular kind of cancer. But some advocates say that concern is misplaced, particularly with more common kinds of cancer.

The geographical information on cancer patients is admittedly imperfect. It shows where they lived when their cancer was diagnosed or when they died. Experts say it would be better to know how long the patients had lived at those addresses, their previous addresses and their workplaces. Survivors' groups have long pressed the state to include that information in the registry, to no avail.

"What they have is certainly a very good start for pointing where researchers should look," said Dr. J. R. Nuckols, associate professor of environmental health at Colorado State University and director of the university's Environmental Health Advanced Systems Laboratory. "And then, in those places, you would need to do some very intensive field-level epidemiological legwork."

Some advisory committee members say Health Department officials told them in December that the initial maps, at least, would contain no data on environmental hazards.

"That defeats the whole purpose of mapping," said Judith Enck, environmental analyst at the New York Public Interest Research Group.

Ms. Smith said the department had not yet decided whether to include pollution data in the first maps. She said that eventually, "we intend to do risk factors mapping," but that she did not know when that might be.

When asked why environmental factors would be left out, she said, "We have a responsibility to give people information that's as clear and understandable as possible."

Advisory committee members say the department is extremely reluctant to indicate any connection between polluters and cancer.

"They're struggling with developing the methodology, and they're very concerned about what will be represented as a link between cancers and environmental factors," said Sarah Meyland, a panel member and executive director of Citizens Campaign for the Environment.

But the map was never intended to establish such a link; scientists say it cannot establish a link. That can only be done by intensive field work, including chemical and biological testing. The map, they say, is only meant to show where to look.

"A map can't prove cause and effect," said Dr. Juna Fessenden MacDonald, biochemistry professor at Cornell University, director of the university's Breast Cancer and Environmental Risk Factors Program and an advisory committee member.

Like some other scientists on the panel, she said she was comfortable with the department's approach, which reflects research scientists' habit of publishing findings only after they are fully refined. "I think they intend to do the environmental overlays, eventually," she said.

But another panel member, speaking on the condition of anonymity, said, "I think they want to stall this issue and hope it just goes away."

Advisory committee members said they were told at the December meeting that the state would map lung cancer first. Lung cancer has a strong environmental link, but it is overwhelmingly to smoking, not the kind of pollution with which the project is concerned.

Ms. Smith insisted that the department had not decided what cancer it would map first, and in fact, might map several types at once.

Breast cancer groups say they will be furious if breast cancer is not among the first mapped, because they were a driving force behind the project and breast cancer, like liver cancer, is suspected of having a strong link to environmental factors.

"This whole project started with us," Ms. Pace said. "If breast cancer isn't included in the first round, they're going to have some explaining to do."

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Breast Cancer Clusters May Start in Childhood

By Cat Lazaroff

BUFFALO, New York, June 26, 2002 (ENS) - Researchers seeking the environmental triggers of breast cancer may need to look far back into a woman's past, suggests a novel study by geographers and epidemiologists at the University at Buffalo (UB). Where a woman lives at birth and puberty may have an impact on her risk of developing breast cancer later, the team concluded.

The researchers compared residential history data provided by women with breast cancer and a control group without cancer in western New York. Using geographic positioning technology, the researchers showed that the women who developed breast cancer were more likely to have lived closer together at birth and at their first menstruation - a concept called clustering - than women who did not develop breast cancer.

The findings indicate that there may be something in the environment close to these clusters that influences a woman's breast cancer risk, said Dr. Jo Freudenheim, professor in the department of social and preventive medicine in the UB School of Medicine and Biomedical Sciences, and senior author on the study.

A woman performs a self examination looking for changes that may indicate breast cancer. (Photo courtesy Columbia University)

Only a few prior studies have examined these time periods for cancer risk, and none have focused on environmental exposures, Freudenheim said.

"Not too long ago, researchers were looking only at relatively recent environmental exposure, maybe in the last 10 years, when we were studying the relationship of environment to breast cancer risk," Freudenheim said.

"Recently we've come to understand that breast cancer risk may be

influenced by events early in life. These data support that hypothesis," said Freudenheim. "The next step is to identify where these places are and see if we can identify exposures that explain the clusters."

Freudenheim is principal investigator on a three year project funded by the U.S. Department of Defense to study the possible link between breast cancer and early environmental exposure to potential carcinogens. Some of the first findings of that research were presented June 21 at the annual meeting of the Society for Epidemiological Research.

The project piggybacks on Freudenheim's ongoing case control study of breast cancer in Erie and Niagara counties in Western New York, which involves 1,170 women with breast cancer and 2,116 healthy women. Of this total, 1,073 women who were born in either of the two counties and had provided the address of their residence at birth became the focus of the current research.

UB geographers and epidemiologists are entering residential data into a computerized mapping program, along with the location of steel mills, chemical factories, gasoline stations, toxic waste sites and other industrial sites in existence in the two counties between 1918-80.

They then will calculate the distance between these sites and the women's homes at the time of birth and menarche - the date of their first menstruation - and compare this information for the participants with and without cancer.

These early data revealed the greatest clustering of cancer cases at the time of menarche, said Daikwon Han, a graduate student in geography who is first author on the study. Some clustering also was evident for place of birth, he said, but there was no clustering effect for the women at the time they first gave birth

The biomedical research building at the University of Buffalo. **(Photo courtesy UB)**

"Researchers think the breast tissue may be more sensitive to environmental insults in childhood and that exposures early in life could increase the risk of breast cancer in adulthood," said Freudenheim. "After a first birth, a woman's breast cells may become more resistant to environmental insults. This project is a really good chance to learn more about the role of environmental exposures during infancy and menarche on health and disease later in life."

One out of every eight women in the United States will develop breast cancer, cancer experts say. Worldwide, 600,000 cases of breast cancer are diagnosed each year.

Breast cancer is the second leading cause of death in women.

The current research was supported by a grant from the Department of Defense Breast Cancer Research Program and from the National Institutes of Health.

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SECTION: AREA/STATE; Pg. B-1

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HEADLINE: RESULTS DISCOURAGE RESIDENTS;
BUT EXPERT SAYS STUDY WAS ONLY FIRST STEP FOR RAYON PARK

BYLINE: Meredith Fischer, And Paige Akin, Times-Dispatch Staff Writers, Contact Meredith Fischer at (804) 649-6452 or mfischer@timesdispatch.com, Contact Paige Akin at (804) 649-6671 or pakin@timesdispatch.com

BODY:
Rayon Park residents feel hopeless now that an official from the state health department said he can't trace the source of their illnesses.

A **cancer-cluster** study, released last month, left more questions than answers for those residents who live next to the Defense Supply Center Richmond, a known contamination site.

"I really don't know what happens next. Where do we go? What do we do? We're just totally disgusted. Sometimes, I feel like I just can't talk about this anymore," said Rayon Park resident Pat McCoy. "But if we quit, we lose the only voice our community had." Despite these findings, Stephen Lester, a health and contamination expert, urged residents not to give up. Now more than ever, he said, they must work together to determine why they're so sick.

In an interview this week, Lester called the cancer study "only the first step." Next, he said, health officials must take a close look at other illnesses that are prevalent among residents.

"This cancer study could not, by itself, provide a definitive answer. This study is not an adequate study to determine whether residents have an increased risk for illness," he said.

Dr. William Nelson, the Chesterfield County health district director, concluded that Rayon Park residents are not at an increased risk for cancer.

"It is not my job to make people believe something they don't want to believe," Nelson said. "It's my goal to do a job and do it right."

The study confirmed 26 cancer cases - mainly colon, rectal or lung - among Rayon Park residents who lived there between 1985 and 2000. Rayon Park is next to the supply center.

While Nelson said the large percentage of colon and rectal cancers among Rayon Park residents "stands out," he said there was nothing alarming about the percentages of other types of cancer. In fact, some were lower than normal for Chesterfield County residents, he said. In Rayon Park, about 31 percent of cancers reported were colon or rectal; countywide, those two types account for about 11 percent of all cancers.

Lester, the science director for the Center for Health, Environment and Justice in Northern Virginia, said scientists know little about how the body responds to small amounts of many chemicals.

He worked with the community in New York affected by Love Canal, where residents reported elevated rates of miscarriages, birth defects, urinary diseases and nervous breakdowns - not just cancer.

"Any time you do a study like this with a small group of people, it's really hard to find an effect," he said. "It's really not a function of whether there's a problem. It's a function of the number of people."

Patricia King, 34, has had four miscarriages since 1999. She lost the last baby in June, when she was 3 1/2 months pregnant.

"So far, the doctors haven't been able to tell me why this keeps happening," she said. "We wanted one more child. And, God willing, we will have one."

King has two daughters, Heather, 9, and Stephanie, 13. She had one miscarriage between the two girls and believes that growing up in Rayon Park might be to blame for the problems she's had carrying pregnancies to term.

"I've wondered about it," she said. "My mother has tried to find out, especially since my aunt has lupus, my brother has problems and my father had a partial stroke when he was really young. We all lived there and my mom and dad still do. I try to go day by day."

King says the last few weeks have been difficult for her.

"It's worse at times," she said. "It will be really hard at Christmas. That's when the baby would have been born."

For decades, the center leaked a number of potentially dangerous substances into the ground and the water that runs through Rayon Park, a community of more than 90 homes along Jefferson Davis Highway.

One contaminant repeatedly dumped at the center was trichloroethene, a popular cleaning solvent and degreaser used for years at the center. When consumed or breathed, TCE is metabolized by the liver and at high concentrations can damage the lungs, liver and central nervous system, experts said.

For decades, the center served as one of the nation's largest military supply facilities. It was also a dumping ground for chemicals that were stored, buried or spilled. In 1987, it was designated a Superfund site, and a federally funded cleanup was ordered.

"We need someone to help us," said resident Lonnie McCoy. "I've lived through all of this. I've heard every piece of evidence. But what do you do when you believe there is a big cover-up?"

Lester said Nelson called him two weeks ago to "discuss how to interpret the data" from Nelson's cancer research. Lester declined to comment without having seen the data firsthand, he said.

"I didn't receive a copy of the report until this week," Lester said.

He suggested that the Restoration Advisory Board, a group of local officials and citizens who act as community liaisons for cleanup at the center, look into sponsoring an independent technical adviser to help them digest complex scientific data.

Also, Rayon Park residents should consider setting up an independent medical clinic for diagnostic testing, with doctors who are knowledgeable about chemical exposures, he said. That way, the community could get a more complete inventory of its illnesses.

"My advice to them - do not to give up," Lester said. "The community needs to stay involved and perhaps get more involved in determining the next steps."

GRAPHIC: PHOTO

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Cancer Cases at Schools to Be Studied; Health: Board of Supervisors orders county officials to investigate possible clusters in Sun Valley and Carson. Both sites are near landfills.

The Los Angeles Times; Los Angeles, Calif.; Oct 20, 1999; SYLVIA WESTPHAL;

Sub Title: [Valley Edition]
Edition: Record edition
Start Page: 6
ISSN: 04583035
Personal Names: **Yaroslavsky, Zev**

Abstract:

The Board of Supervisors on Tuesday ordered county health officials to investigate cancer cases among teachers and staff at two schools located near landfills.

According to a motion passed Tuesday, the county's Department of Health Services must look into reports of seemingly high cancer rates, also known as a "cancer cluster," among employees at Towne Avenue School in Carson and Polytechnic High School in Sun Valley. The schools are located near landfills, and residents in those areas question whether toxic substances from the sites might be linked to the apparently higher cancer incidence.

Full Text:

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According to a spokesman for Supervisor Zev Yaroslavsky, the county's health services department has known about the cancer concerns since Sept. 23 but failed to inform the Board of Supervisors.

"These issues are not being taken seriously enough by people in the bureaucracy," Yaroslavsky said. "We don't have an excuse; we owe it to the public to either verify if their suspicions are correct or confirm [there is no problem] and put the people's mind at ease".

The motion, drafted by Yaroslavsky and Supervisor Yvonne Brathwaite Burke, instructs the health department to conduct public meetings led by medical and public health staff to answer questions, provide screening for those constituents at risk and establish an 800 number for people's concerns.

Mark Finucane, director of the county's Department of Health Services, stated in a prior memo that he would "ensure that all agencies worked together to expeditiously address all identified public issues."

But there is concern that the department does not have the resources to meet some of these goals. Dr. Jonathan Fielding, director of the health department's Public Health Program and Services, told the supervisors that the department has "a limited ability to conduct tests based on our current staffing."

Credit: TIMES STAFF WRITER

COURT UPHOLDS AWARD AGAINST UTILITY IN CHILD CANCER CASES

St. Louis Post - Dispatch; St. Louis, Mo.; Feb 23, 2002; Kevin McDermott Post-Dispatch Springfield Bureau;

*Sic:***221122**
Sub Title: [FIVE STAR LIFT Edition]
Start Page: 15
Subject Terms: State court decisions
Settlements & damages
Health hazards
Cancer
Classification Codes: **9190**: *United States*
4330: *Litigation*
8340: *Electric, water & gas utilities*
Geographic Names: Springfield Illinois
Dateline: SPRINGFIELD, ILL.
Companies: **AmerenCIPS***Sic:***221122**

Abstract:

The court said it was upholding a lower court ruling against AmerenCIPS of Springfield, stemming from four cases of neuroblastoma that arose in the small town of Taylorville, Ill., about 90 miles northeast of St. Louis.

All four had lived near an abandoned plant, owned by AmerenCIPS, that once made gas from coal. Though there is no proven cause of neuroblastoma, a byproduct of the coal gasification process, called coal tar, has been found to cause other cancers.

The attorney for the children, Thomas Londrigan of Springfield, has argued during the six-year legal battle that the Taylorville "cancer cluster" was caused by the toxins at the AmerenCIPS plant. The company has maintained there is no scientific evidence of that.

Full Text:

LOCAL

* The families of four children from Taylorville, Ill., who were awarded $3.2 million claimed that waste from an abandoned coal gasification plant caused the disease.

The Illinois Supreme Court on Friday upheld a $3.2 million judgment against an electric company for the families of four children diagnosed with a rare form of cancer while living near an abandoned toxic waste site.

The court said it was upholding a lower court ruling against AmerenCIPS of Springfield, stemming from four cases of neuroblastoma that arose in the small town of Taylorville, Ill., about 90 miles northeast of St. Louis.

Neuroblastoma is a rare nerve cell cancer that normally occurs in about one of every 100,000 children. Four children in Taylorville, population 11,100, were diagnosed with the disease in the early to mid-1990s.

All four had lived near an abandoned plant, owned by AmerenCIPS, that once made gas from coal. Though there is no proven cause of neuroblastoma, a byproduct of the coal gasification process, called coal tar, has been found to cause other cancers.

The attorney for the children, Thomas Londrigan of Springfield, has argued during the six-year legal battle that the Taylorville "cancer cluster" was caused by the toxins at the AmerenCIPS plant. The

company has maintained there is no scientific evidence of that.

The state high court's ruling upholds an appellate decision to let stand a $3.2 million verdict originally rendered in March 1998.

"This case presents the classic 'battle of the experts,' frequently seen in toxic tort litigation," Justice Thomas Fitzgerald wrote. Nonetheless, there was "sufficient evidence from which a jury could conclude that CIPS's conduct was a ... substantial factor in bringing about the alleged injury."

There was no dissenting opinion from the court.

The families' attorney couldn't be reached for comment Friday. He said last year that one of the four children in the case had died of the disease during the litigation.

AmerenCIPS said in a written statement it was disappointed and was studying the decision.

"It remains the position of AmerenCIPS that there is no known cause for neuroblastoma," said the statement. The company said it did not expect the decision to affect customer rates.

The Nuke Next Door

Do Cancers Cluster Around Atomic Plants?

April 30, 2004 | Trish Riley

{image_caption} {image_matrix limit="3"} {/image_matrix}

Raised on fresh fruits and vegetables by his vegetarian mother, Ty-Michael Schmidt never even had a cold or ear infection before the age of five. Then doctors found a tumor in his abdomen. His mother, and some scientists, suspect the tumor has something to do with the fact that he lives near a nuclear power plant.

"I never knew a child with cancer until my son," says Audra Schmidt of Hobe Sound, Florida. "Now I know nothing but kids with cancer. At least 50 kids in our local area have it."

But there's not a cancer cluster in the neighborhood, according to the St. Lucie County, Florida Health Department, which conducted an in-depth study of the homes of 28 children with cancer. During the same period, another 12 cases were identified in near-by Martin County. Tests were conducted on water, soil, air and dust for 561 different chemicals and potential contaminants. The results were negative for all chemicals tested.

"We have yet to find any commonality," says James Moses, director of environmental health for St. Lucie County. "We are dealing with 30 cases from 1981 to 1997. There was no cancer cluster."

The study continues, though, because it did find a marked increase in childhood cancers of the brain and central nervous system: 15 diagnosed in three years, nine within a seven-month period. The report notes that the trend should be monitored and perhaps studied further.

Health officials did not test for Strontium 90 (Sr-90), a radioactive carcinogenic byproduct of nuclear fission. The Radiation and Public Health Project (RPHP), a nonprofit research center in New York City, recently released a study linking increased incidence of childhood cancers to areas near nuclear power plants. The study was published in the peer-reviewed Archives of Environmental Health last year.

"Of the 14 areas studied, the two counties closest to the reactors in St. Lucie County had the highest cancer rates," says principal researcher Joseph Mangano, national coordinator of the RPHP. Mangano says the Florida State Cancer Registry lists four cases in St. Lucie County for children under 10 from 1981 to 1983, but this increased to 30 cases from 1996 to 1998. Accounting for a near doubling of population, the incidence still represents a 40 percent increase, compared to an average national increase of 11 percent in childhood cancers.

The RPHP has also been studying radiation levels in baby teeth of children around the country. Dubbed the Tooth Fairy Project, (see Your Health, "Glowing in the Dark," May/June 2002), researchers report higher levels of Sr-90 near nuclear power plants, including St. Lucie and Miami-Dade counties. Water samples indicate higher levels of Sr-90 in areas within 20 miles of the nuclear power plants than in more distant locales. The study also found that the levels of Sr-90 in the teeth of children diagnosed with cancer were nearly twice as high as levels in children who do not have cancer.

These results are hotly disputed by the multi-billion dollar nuclear power industry. "Their claims are false," says Rachel Scott, spokesperson for Florida Power and Light, which owns the St. Lucie and Miami's Turkey Point nuclear power plants. "Cancer levels are not higher in South Florida. The levels of Strontium 90 are not higher in South Florida, according to the Florida Department of Health and the

Nuclear Regulatory Commission."

The nuclear industry blames any Sr-90 still in the environment on residual effects of bomb testing. But a U.S. Environmental Protection Agency report says because of decay, insignificant levels of Sr-90 remain in the soil and atmosphere from the bomb tests that ended 40 years ago.

"This touches a nerve in the nuclear power industry," says Stephen Lester, science director of the Center for Health, Environment and Justice (CHEJ). "These plants are releasing small quantities of low-level radiation every day. The amounts may seem insignificant, but when you look at 50 cities, you can see it slowly has an impact."

At least two families were sufficiently convinced to file suit against Florida Power and Light because of their children's illnesses, which include one death. "A huge thing at stake here is the state of nuclear power plants," says Nancy LaVista, attorney for the plaintiff families. "If in fact it is giving cancer to our children, we have a right to know and a duty to protect all citizens of Florida."

St. Lucie and Martin County families have joined forces to create a packet detailing their children's illnesses. "It's not so much for our children, who are already sick," says organizer Debi Santoro, whose four-year-old daughter, Jadyn, contracted cancer when she was six months old. "It's for the children to come. These children are dying and they're not going to die in vain—they're going to help other children." In another part of the country, New York's Westchester and Suffolk counties and the state of New Jersey have appropriated funds to study areas near nuclear plants where cancer clusters are suspected.

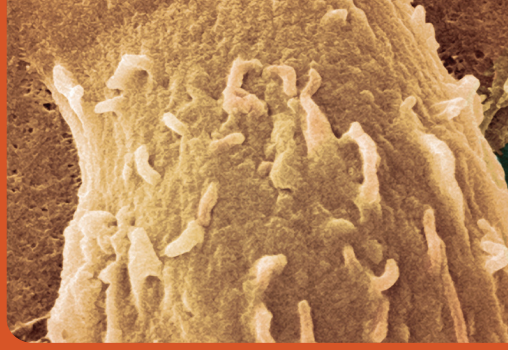
A 2003 report released by the European Committee on Radiation Risk found the risk from low-level radiation to be significant, concluding that "the present cancer epidemic is a consequence of exposures to global atmospheric weapons fallout in the period 1959 to 1963 and that more recent releases of radioisotopes to the environment from the operation of the nuclear fuel cycle will result in significant increases in cancer and other types of ill health."

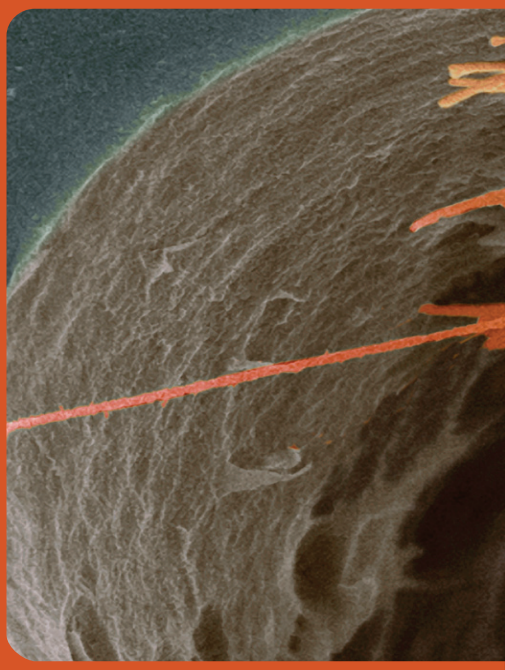
Meanwhile, U.S. industry officials insist on labeling the reports "junk science," and eagerly push a nuclear energy agenda. The federal government and the Nuclear Regulatory Commission are currently promoting legislation to renew interest in nuclear power and encourage the development of more new nuclear power plants for the first time since the Three Mile Island nuclear accident in 1979.

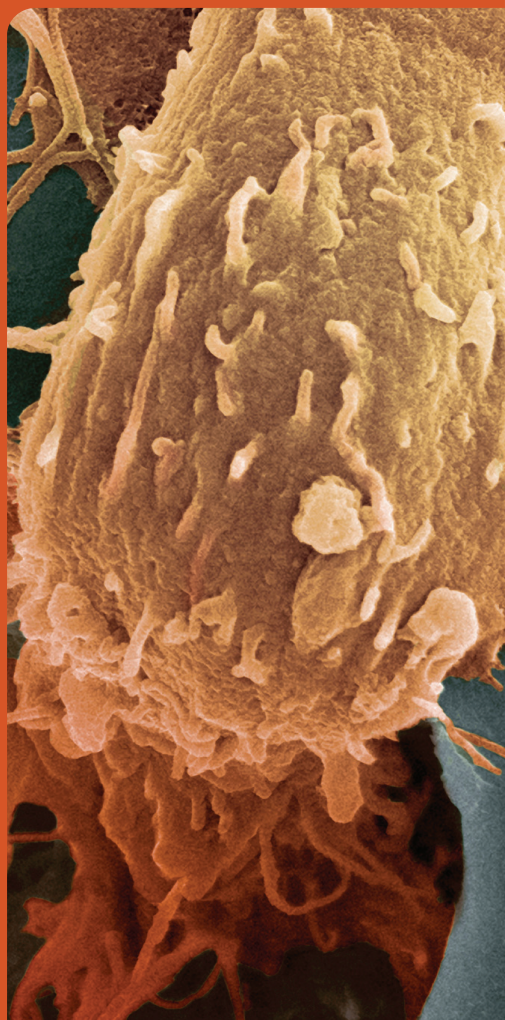
Stephen Lester of CHEJ suggests the power industry adopt his organization's new Be Safe Campaign. "It's based on the fundamental principle of public health that says, "if it is dangerous or has the potential to harm, proceed with caution.""

Now 10, Ty-Michael Schmidt spent a year in the hospital undergoing radical experimental treatment for a rare form of cancer. Doctors have never been particularly encouraging about his prognosis, giving him only six months to live when he was diagnosed four years ago, but he is in remission and he's beaten the odds thus far. Doctors say his cancer can be traced to fetal cells, meaning it developed in utero.

For now, RPHP researchers recommend that concerned people try a remarkably simple precaution: drink only water that comes from a deep, protected source or that has been filtered to remove Sr-90 particles (such as by reverse osmosis). If only Audra Schmidt and the dozens of other parents of ill children in her community had known that.







"CHEJ is the strongest environmental organization today – the one that is making the greatest impact on changing the way our society does business."

Ralph Nader

"CHEJ has been a pioneer nationally in alerting parents to the environmental hazards that can affect the health of their children."

New York, New York

"Again, thank you for all that you do for us out here. I would have given up a long time ago if I had not connected with CHEJ!"

Claremont, New Hampshire

Center for Health, Environment & Justice
P.O. Box 6806, Falls Church, VA 22040-6806